How do People with Learning Disabilities Understand Citizen Inquiry?

Thesis

How to cite:

For guidance on citations see FAQs.

© 2017 The Author
Version: Version of Record

Copyright and Moral Rights for the articles on this site are retained by the individual authors and/or other copyright owners. For more information on Open Research Online’s data policy on reuse of materials please consult the policies page.
Jessica Carr BA (Hons)

Title: How do people with learning disabilities understand citizen inquiry?

Masters of Research (MRes)

6th September 2017

The Open University
Abstract

One question often asked is whether people with learning disabilities are regularly excluded from decision-making processes which may have a direct impact on them. This study uses citizen inquiry research methodologies to engage adults with learning disabilities in scientific inquiry through the use of participatory research approaches. It is aimed at learning how people with learning disabilities understand citizen inquiry and what levels of support are required for future work in this area. A group of six participants, from the Monday night social group at Yellow Submarine Charity (www.yellows submarine.org.uk), engaged in a citizen inquiry project run over four 1 hour sessions. The sessions were aimed at gaining data on how the participants understood citizen inquiry through ethnographically-informed observation and a focus group. Through the analysis of the data, I found that participants understood citizen inquiry in two ways; what they believe a citizen to be and how the project made them feel. Often, the participant's responses were positive in nature but identified a need for future research into their understanding of citizen inquiry. Whilst people with learning disabilities are routinely excluded from decision-making processes, the inclusive nature of this research and the way in which citizen inquiry works allowed for the participants to have a positive experience whilst gaining autonomy in their decision-making.
Contents
1. Aims and Objectives ........................................................................................................... 4
   1.1 Introduction ......................................................................................................................... 4
   1.2 Aims .................................................................................................................................. 4
   1.3 Objectives .......................................................................................................................... 5
2. Literature Review ................................................................................................................. 7
   2.1 Definitions of citizen science and inquiry ......................................................................... 7
   2.2 Influencing factors for how people with learning disabilities understand citizen inquiry .... 9
   2.3 A case for adopting an inclusive research framework .................................................... 13
   2.4 Support required for citizen science projects when working with people with learning disabilities ........................................................................................................... 14
   2.5 Conclusion ...................................................................................................................... 16
3. Methods of data collection ................................................................................................... 17
   3.1 Research approach – inclusive research ........................................................................ 17
   3.2 Research paradigm – critical theory, normalisation and participatory research .............. 18
   3.3 Research methods – ethnographically informed observation and focus groups ............ 20
   3.4 Ethics ................................................................................................................................ 21
4. Collecting and analysing the data ....................................................................................... 24
   4.1 Collecting the data ............................................................................................................. 24
   4.2 Analysis of the data .......................................................................................................... 26
5. Interpreting the Data ............................................................................................................ 29
   5.1 Session explanation ........................................................................................................... 29
   5.2 Community ....................................................................................................................... 30
   5.3 Support ............................................................................................................................ 31
   5.4 Engagement ..................................................................................................................... 33
   5.5 Identity ............................................................................................................................. 35
   5.6 Discussion ........................................................................................................................ 37
6. Findings ............................................................................................................................... 40
   6.1 Assessment of findings .................................................................................................... 40
   6.2 Limitations of the study .................................................................................................... 42
   6.3 Future Work ..................................................................................................................... 43
Bibliography ........................................................................................................................... 45
Appendix A ............................................................................................................................. 49
Appendix B ............................................................................................................................. 50
Appendix C ............................................................................................................................. 51
Appendix D ................................................................................................................................ 52
Appendix E ................................................................................................................................ 53
Appendix F .................................................................................................................................. 54
Appendix G .................................................................................................................................. 55
Appendix H .................................................................................................................................. 56
Appendix I .................................................................................................................................. 59
1. Aims and Objectives

1.1 Introduction

This dissertation aims to address an imbalance of power between ‘experts’ and ‘non-experts’ often found within scientific inquiry. In doing so this dissertation challenges processes through which people with learning disabilities are regularly excluded from decision-making processes which may have a direct impact on them. For this study I will use the term ‘learning disabilities’ to cover a broad range, including those with ASD (Autistic Spectrum Disorder). This study documents the findings from research where participants were supported, through technology and mentoring, to take on expert roles in citizen inquiry, giving them the lead voice within research-based decision-making.

Through the use of inclusive and participatory approaches (Walmsley and Johnson, 2003) to research this project facilitates a citizen inquiry project that engages adults with learning disabilities in the process of scientific inquiry. Citizen inquiry, is linked strongly to both the theories of citizen science and inquiry-based learning (Villasclaras-Fernandez et al., 2013:383), with an emphasis on a ‘supportive community’. This links it to social research which offers a reflexive environment to support the needs of the participants and to give them the chance to have a voice in the decision-making process.

My interest in studying this topic is linked to my previous experience working with people with learning disabilities. I have worked with both adults and young people with learning disabilities who participated in structured employment training schemes, designed to prepare them for paid employment through the charity, Yellow Submarine (www.yellowsubmarine.org.uk). Through this work I have reflected on the many ways in which opportunities can be facilitated to enable this community to engage more fully in their citizenship rights and obligations. I believe the involvement in citizen inquiry, specifically in the decision-making processes about policy issues that affect their lives, is a fundamental citizenship right. From this a desire to give a voice to people with learning disabilities within research was founded, and is a central issue within this research project. This also created an interest in the use of inclusive research techniques.

1.2 Aims

The aim of this dissertation is to understand how people with learning disabilities engage with citizen inquiry in order to explore the following research questions:

1. What do people with learning disabilities understand by citizen inquiry?
2. What forms of support are required for citizen inquiry projects when working with people with learning disabilities?
3. Does the nQuire-it platform support engagement for people with learning disabilities?

These research questions were identified from gaps within the literature which I will further discuss in the literature review.

Having outlined the aims of this project, I will now move on to discuss how the objectives for the project will enable me to achieve these aims.

1.3 Objectives

Morris (2005) introduces three concepts that she argues are essential for people with learning disabilities to achieve citizenship; self-determination, contribution and participation. In chapter 2 of this dissertation I will discuss each concept in more detail. I argue there is a link between these concepts and citizen inquiry. Citizen inquiry is aimed at engaging citizens in the research process. It provides a set of principles whereby all citizens, including people with learning disabilities, can explore their self-determination, contribute to scientific inquiry and participate in different projects relating to issues in which they have an interest.

In order to explore this link further, my first objective was to create a framework to guide both the fieldwork and the analysis of the data. Through identifying gaps within the literature I was able to develop three themes which came together as a framework as displayed in Box 1.

**Box 1. My analytical framework**

```
[Diagram: Support, Engagement, Community interlinked]
```

This framework was also developed through the examination of the principles of inclusive research. Walmsley and Johnson (2003) introduce three principles in which to guide inclusive research. Briefly, the first principle focusing on the aim of research and that it addresses issues important to the participants. The second principle looks at the relationship between researchers and the participants, and the third principle focuses
on ensuring research is representative of the participants views (pg.16). These three principles linked with Morris’ (2005) concepts influenced the three themes within my framework (Box 1.) My second objective was to use inclusive research in order to access the views of my participant group in a safe and respectful manner, ensuring that the research was with the participants not on them (Nind, 2008: pg 4-5).

My third objective was to negotiate access to a relevant participant group, with whom I could conduct a citizen inquiry project. Yellow Submarine, offered a safe environment in which the participants already knew me through my previous work with the charity. Furthermore, the managers of the charity already knew how I worked and gave me a large amount of support whilst allowing me to conduct my sessions in a way that I saw fit.

To summarise, my first objective of this study was to create a framework which could be used to explore the link between Morris (2005) concepts of citizenship and the concept of citizen inquiry, but also to guide the study on the whole. The second objective was to develop an inclusive and participatory research methodology which would facilitate the engagement of people with learning disabilities. Finally, the third objective was to put this approach into practice in a way that would enable me to successfully answer my research questions outlined above.
2. Literature Review

In order to demonstrate the importance and relevance of my research questions I will discuss four main issues:

1. Definitions of citizen science and inquiry.
2. The influence of factors on how people with learning disabilities understand citizen inquiry.
3. Adopting an inclusive research approach when studying the engagement of people with learning disabilities in citizen inquiry.
4. Finally, I will make a case for the support required for people with learning disabilities when working with citizen inquiry projects

2.1 Definitions of citizen science and inquiry

Citizen science covers two concepts, science and citizenship. Allgaier (2010: pg 4) claims that citizenship, when spoken about in a political concept, implies that citizens have both ‘rights’ and ‘duties’. The example he offers is how a citizen has the duty to participate in decision-making that will affect themselves and their society. This is what he calls a ‘scientific citizenship’, where citizens have the ‘right’ and ‘duty’ to engage with scientific knowledge, more specifically in the way science affects their lives, claiming that it is their responsibility to engage. Yet, he fails to mention citizens who may need support, for example marginalized communities including people with learning disabilities. Furthermore, he fails to discuss the ‘rights’ and ‘duties’ of science communicators. I argue that science communicators should ensure that all citizens have the opportunity to engage with science and to build their ‘scientific citizenship’.

Research within learning disability studies shows this community can be less capable at decision-making. However, when they are given help and an opportunity to be involved in the process, they show their capabilities. (Wehmeyer, 2014: pg.39). It is the exclusion from this decision-making that made them less able.

In a study supported by the BBSRC ‘NanoDialogues’ (2005) a group of citizens were engaged in a ‘citizen jury’ process. During the process, the participants identified recommendations for more engagement and appropriate support by scientists. This, I argue, also relates to those with learning disabilities as representatives of wider society. Responsibility for their exclusion to be involved cannot lie solely with the citizen. Instead, the people holding more power and resources in which to frame these processes within the field should address the issue and offer support.

In the recent House of Commons Select Committee Report on Science Communication and Engagement (2017) they identify ‘a collective need to do more to take science to those who are not currently engaged’ (pg.3). Within this report, they identify different
ways to do this, specifying strategies for particular groups of the community. For example, certain events such as ‘Cheltenham Science Festival’ are cited within this report as increasing the ‘visibility of science communicators (and) have significantly raised the profile of public engagement with science’ (pg. 10.). This identifies a need for studies such as this one, to bring science to communities who are not engaged.

Much has changed since Irwin (1995) published his influential text ‘Science and Citizenship’. For example Irwin cites the Royal Society and their 1985 report on public understanding of science. Briefly, it claims a ‘notion of pubic ignorance’ (pg.14) about science and technology, claiming that a ‘better understanding of science will lead to better public and personal decisions’ (pg.14). It focuses on this ‘ignorance’ and makes the responsibility to engage with science mainly the citizens. The current strategy of the Royal Society (2017) states that:

‘through engagement with different groups in society and with the public in general, the Society will aim to ensure that its work is informed by broader views and that science is included as part of wider public conversations.’ (pg.5)

Here we can see how the views in the professional science communities have grown and adapted to the belief that it is their responsibility to engage with the general community.

Irwin (1995) later claims that ‘citizens are impoverished by their exclusion’ (pg.26) from science. I argue that this is still applicable and that the learning disabled community are at risk of being impoverished. Following Irwin and Allgaier’s ideas, in order for citizens to gain their ‘scientific citizenship’ they must be exposed to scientific inquiry. If we are to agree with Irwin, then it could be argued that Allgaier’s (2010) arguments of the rights and duties of citizens are slightly flawed. As mentioned earlier, to tackle this issue of impoverishment would be the responsibility of science communicators not only citizens.

Allgaier (2010) discusses another form of exclusion he believes present within citizen science, the ‘self-selection process of the participants’ (pg.132). He argues that many of the participants involved in citizen science projects, already have an interest in scientific inquiry. While some citizen science projects will only appeal to those with prior scientific knowledge, projects such as ones undertaken in educational settings can be introduced to people with little or no such knowledge. For example, iSpot, a ‘social learning website’ aimed at members of the general public. It encourages people to ‘participate in real science through recording nature observations’ (Scanlon et al., 2014: pg.3). This is evidence that citizens without knowledge of science can engage, when given the opportunity.
It is the ‘non-experts’ found in these communities that are equally important to citizen science. Using the theory of a ‘scientific citizenship’ and Irwin’s idea that people who aren’t engaging in science are ‘impoverished’, engaging people with learning disabilities in scientific inquiry ensures that all citizens are valued. Whilst this study aims to see how adults with learning disabilities engage in scientific inquiry, it should offer an opportunity for the participants to understand their ‘rights’ and ‘duties’ within society, and to engage with these responsibilities.

**Citizen inquiry and its position within this broader field**

Aristeidou (2016: pg 16) identifies in her thesis that ‘Citizen Inquiry, unlike many citizen science projects, engages citizens in all the stages of the scientific process and its main focus is on learning about the scientific process’. This allows for a more diverse set of topics to be studied and for participants to engage with the process of research. This is why I have chosen to replace citizen science with citizen inquiry here. It lets the participants discuss and research topics which affect them and their communities. Both forms of engagement use the rigorous methods of enquiry to research subjects which are of interest to or have an impact for citizens. ‘Science challenges citizens and researchers alike to address daily complex problems and concerns’ (Ruiz-Mallen et al., 2016: pg. 524)

As discussed in chapter one citizen inquiry directly aims at offering ‘supportive communities’ in which people can use ‘authentic science practices’ to research topics of relation and importance to themselves. (Villasclaras-Fernandez et al., 2013:383). These supportive communities are created by the sharing of knowledge treating participants as useful partners. This helps to scaffold participants as they overcome barriers to their learning and creates a safe environment in which to participate and discuss. This emphasis on a ‘supportive community’ is why I have chosen to use citizen inquiry, as it offers a much more flexible approach to support the needs and requirements of the participants.

**2.2 Influencing factors for how people with learning disabilities understand citizen inquiry**

Through my reading of the literature I have identified two main factors that might influence how people with learning disabilities understand citizen inquiry:

1. Exclusion on the grounds of scientific illiteracy.
2. Different experience and opportunities to enact citizenship.

**Exclusion on the grounds of scientific literacy**

Throughout the citizen science and inquiry literature, citizenship and its relationship with science is often referred to, referring to the population as a whole. There is little literature which refers to people with learning disabilities and their ability, or not, to
engage in science as a topic. The Special Educational Needs and Disability code of practice (Department for Education and Department of Health: 2008) discusses at length the importance of removing barriers to young people and children within education stating, ‘those working with children and young people with SEN or disabilities [must] include them in all the opportunities available to other children and young people so they can achieve well’ (pg.27). Later in the document, when discussing the curriculum, they mention again the importance of removing barriers. ‘In many cases, such planning will mean pupils with SEN and disabilities will be able to study the full national curriculum’ (pg.94) While this states the importance of encouraging pupils to engage with science it does not state how teachers should ‘address potential areas of difficulty’ (pg.94) or what these may be. I would argue that by having a strong focus on the scientific aspect of citizen science, participants are excluded from engagement if they are not considered to hold sufficient ‘expertise’ in this broad field. Issues arise here with the word ‘expertise’. It could have two meanings, one which focuses on ‘expertise’ gained from first-hand experiences such as people with learning disabilities informing research with their own community. Secondly it could focus on the sort of ‘expertise’ gained by researchers or scientists, more theoretical. To exclude the first meaning of this term from research, is to exclude those who may only have first-hand experience. The main form of exclusion occurs when the ‘so-called science expert’ seeks to exclude the ‘so-called novices’.

Durant (1994) argues that ‘Scientific literacy should not be taken to mean the knowledge of a lot of science, but rather the understanding of how science really works’ (pg.83). This definition is much less exclusive to ‘scientists’, instead introducing the issue of how ‘non-experts’ are given the opportunity to understand ‘how science really works’.

Within his article, he identifies how scientific literature is different to scientists and the general public, highlighting the question of authenticity. That doing science in the way that citizen inquiry demands, focusing on the process not necessarily the outcome or the data itself, offers an authentic experience. One that allows citizens to encounter science and research in a safe environment so that when they encounter it again, they have an ‘understanding of how science really works’ (pg.83) In his final statement, Durant claims that: ‘We need to consider how a truer picture of science can be conveyed to a general public which has no direct experience of scientific research at all’ (pg.89). Throughout the article, Durant is arguing for a more authentic view of science to be made available to citizens. I argue that what has been highlighted in the literature is a need for direct involvement in scientific research. Instead of considering public image and how to adapt it, the focus should be on how to engage the public in a scientific literacy that reflects Durant’s original definition. This is why this research
study is of particular importance, not just to citizen inquiry but to science as a field and their engagement with people with learning disabilities.

Different experiences of and opportunities to enact citizenship

In a steering paper by Morris (2005) focusing on people with learning disabilities there is an argument against Allgaier’s (2010) ‘rights’ and ‘duties’ of citizens. This is evident in Morris’ concept for achieving citizenship, ‘contribution’. Whilst talking about ‘contribution’ Morris highlights that ‘current debates on citizenship focus on the need for individuals to fulfil certain responsibilities and there is a strong assumption that it is the fulfilment of these responsibilities that qualifies them for full citizenship’ (2005: pg.26).

As I argued earlier, the ‘citizenship’ which is referred to within the literature surrounding citizen science is that of every citizen, not a specific section of society. Citizenship, applies to different communities in different ways. For example, the learning disabled community may not be fully able to fulfil their ‘responsibilities’ due to social or physical restrictions because of their disability, which raises problems of being treated as less of a citizen because of this. The solution to this is to work with communities to identify their wants and needs so that future work can be structured to them.

Broadly speaking people with learning disabilities may be unable to fulfil their responsibilities due to their oppression in society. Writing in the context of research, Nind (2008: pg.4) states: ‘Traditional qualitative research is likely to encompass substantial barriers between the powerful researcher and the less powerful researched’. Here, she identifies the difference for people with learning disabilities and introduces questions of equity. How can this form of research ensure that it equitable to both participants and researchers? There are barriers stopping the achievement of equity and these would have to be removed in order to achieve this. One barrier is the distribution of power between researcher and participant. The learning disabled community are often viewed as ‘the less powerful’ due to the stigma surrounding their disabilities which hinders their ability to engage with their citizenship ‘rights’ and ‘duties’. This study aims to redress this balance within research, offering the possibility to remove barriers and encourage engagement.

Morris (2005) offers a number of reasons why people with learning disabilities may be less powerful. In a research context, the researcher has the ability to control their own power relations through their choice of methods and/or facilitation approaches. Morris’ concepts help to assist the adaption process, by identifying three key themes which can inform researchers during the review process of their facilitation. Morris’ first concept is ‘self-determination’. She states that ‘if self-determination is a key aspect of what it means to be a ‘free and equal citizen’ then this should be our aspiration for all disabled people’ (pg.11). She argues that a lack of autonomy for people with disabilities
creates a barrier to their self-determination. The difference between self-determination and autonomy lies within the idea that self-determination is a process in which a person gains control of their life, whereas autonomy is the freedom and independence that allows them to do this. This lack of autonomy stems from discrimination and exclusion within society and limited equality in terms of opportunities to participate in decision making. This has the potential to have implications on this community’s engagement within citizen inquiry. Although offering a supportive environment in which to pursue scientific inquiry, citizen inquiry also requires self-determination. The projects are created by the citizen’s, meaning there must be a level of self-determination in place to begin the inquiry. It could also be argued that because of the supportive environments in which autonomy is encouraged the barrier Morris discusses would be removed and self-determination would be facilitated.

In Morris’ second concept, ‘participation’, the issue raised is the level to which people are involved in their local community and take responsibility for issues within it (pg.17). She argues that to enable this form of participation to take place for people with learning disabilities, barriers must be removed. The Prime Minister’s Strategy Unit offer four categories of barriers faced: attitudinal, policy, physical and empowerment (2005). Within citizen inquiry, empowerment is the key barrier which may be affected. As discussed previously in section 2.1, citizen inquiry offers a supportive environment in which the participant is encouraged to take on the expert role. For example, the Open University’s Children’s Research Centre (CRC) used the Personal Inquiry ‘Inquiry Cycle’ to empower children to be researchers. It had great success with the children using ‘their insider perspectives’ to impact ‘on policy and practice’ (Kellett et al., 2014: pg.3) The Prime Minister’s Strategy Unit also describe barriers surrounding empowerment ‘as a result of which disabled people are not listened to, consulted or involved’ (2005: pg.8). Citizen inquiry attempts to redress the issue by ensuring that all citizens have an equal opportunity to be involved in scientific inquiry. The power relation is redistributed more equitably between participant and facilitator, through the use of inclusive practices, in order to better engage the participants in citizen inquiry.

Returning to Morris’ (2005) third concept ‘contribution’, the argument put forward is that the current debates around citizenship focus on the ‘responsibilities of citizenship’ and that it is the citizen who must contribute. She argues that instead it should be focusing on the value of ‘contribution to the social good’ (pg. 26), allowing the citizens to have a voice in issues affecting them. As discussed by Gilbert (2004) there is a stigma attached to the word ‘disability’ which routinely exclude this section of society from contribution within social issues and control effecting them (pg.299). Citizen inquiry has the opportunity to address this by removing this power difference.
2.3 A case for adopting an inclusive research framework

It is my contention that the three concepts introduced by Morris (2005), self-determination, participation and contribution, create a clear framework for researchers in the field of citizen inquiry and learning disabilities. Each one identifies separate issues which are vital for the encouragement and engagement of citizenship for people with learning disabilities. I would also argue that they link strongly to the ideals of collaboration and participation within citizen science and inquiry projects. Throughout the literature focusing either on citizen science or citizenship in relation to people with learning disabilities, participation is a word that reoccurs throughout. This conveys what I argue should be the underpinning of all research conducted with people with learning disabilities, that participation is carefully facilitated in order to remove the barriers between the ‘researched’ and the ‘researcher’. Facilitation is key to this, relying on a reflexive process by the researcher to ensure participation is facilitated.

Working with people with learning disabilities in terms of research is a widely debated topic. Nind (2008: pg.5), discusses at length the different views and approaches to research with people with learning disabilities, citing terms such as; emancipatory, inclusive and participatory. These are occasionally differentiated between but also often linked together, as one research method. Stalker (1998) attempts to identify the similarities between these terms, claiming that they are all based on the same three principles. The first, is that the idea of an ‘expert’ role being held by the researcher is ‘inequitable’ (pg.6). The second that it is someone’s right to be involved in research that has an impact on their lives. Lastly, that the research is improved and not hindered by the involvement of people with learning disabilities in the research. These three principles link very closely to the three set out by Morris (2005) as explained above.

Similarly, when discussing the principles upon which inclusive research is founded, Walmsley and Johnson (2003) introduce their own three principles. The first ‘that research must address issues which really matter to people with learning disabilities, and which ultimately leads to improved lives for them’ (pg.16). The second, within inclusive research ‘people with learning disabilities need to be treated with respect by the research community’ (pg.16). Finally, they suggest that inclusive research ‘must
access and represent their views and experiences' (pg.16) These echo the principles identified by Stalker (1998) and link strongly to Morris' (2005) three principles of citizenship for people with learning disabilities.

Inclusive research is described by Walmsley (2004) as a term which contains other branches of disability research such as emancipatory and participatory. She argues that a large proportion of inclusive research focuses on an inspiration to ‘redress wrongs' (pg.66) quoting the idea produced by Barnes (1996) that researchers risk becoming the oppressors when research is done incorrectly. Bigby et al. (2013) introduce further branches of inclusive research discussing a project in which they used what they coin a ‘collaborative group approach’. The study showed that this form of ‘collaborative’ research gave ‘potentially results in better research than either academics or self-advocates could achieve alone’ (pg.55). Although inclusive research covers a broad range of methods, it does address the same issues. As Walmsley (2004) argues, the research must aim to not be ‘value-free’ (pg.65). From all of the literature surrounding inclusive research, this appears to be the key thread.

2.4 Support required for citizen science projects when working with people with learning disabilities
I have identified two potential forms of support that could be employed within citizen inquiry projects when working with people with learning disabilities.

1. Using Technology
2. Using participatory approaches

The Use of Technology
Holliman and Curtis (2015) identify ‘collaboration and participation’ as one of the ‘key trends in the current digital landscape’. Here we can see the clear link between technology and citizen science, where both have the potential to be beneficial to one another. One of these links is the increase in technology for mobile and static devices available for use within citizen science projects. Holliman and Curtis talk about how technology can be accessed ‘wherever and whenever’. This allows researchers to access a wider group of participants, as they can participate in the study in their own time and in their own space or places. One particular technology is the citizen science platform nQuire-it produced by the Open University. During the research process on the platform, it was identified that there were positive learning outcomes and an increase in the enjoyment of science (Scanlon et al., 2014: pg.4). However, there was no research done on the impact and engagement of the platform with people with learning disabilities.

Participatory approaches
There is some evidence to suggest that participatory approaches within citizen inquiry projects can address both issues of citizenship and expertise. Below I will discuss each in turn, with examples from the appropriate literature.

**Participatory approaches – Citizenship**

Identified as a positive effect within environmental citizen science (POST, 2008: pg.2) communities are working together to inform their local authorities through engaging in locally facilitated citizen science projects. The paper produced by POST (2008) discusses how projects that have been collaboratively produced between researchers and local communities, have begun to drive ‘a participatory democracy’ (pg. 2). This relates to mainly environmental science, however it’s a model which could be rolled out to all forms of citizen inquiry, particularly those working with people who are often treated as ‘powerless’, such as people with learning disabilities.

Participatory and inclusive research methods aim to remove this stigma and to offer a safe and open space for people with disabilities to contribute within their community and the researcher community. However, it is important to address the opportunity for further oppression within these forms of research. Swain et al (1998: pg.22) identify this issue as a key feature of research, ‘the essentially political act of research can exploit vulnerable and powerless groups within society, further their disempowerment and contribute to their oppression’. It is the role of the researcher then, to ensure that the research is not oppressive, but instead encourages contribution by the participants. I argue that citizen science, when approached in a participatory manner, allows for these opportunities in decision-making. Nind (2008: pg.5) identifies one issue which must be addressed before research can begin, whether ‘research is on or with people with learning disabilities’. This decision affects whether the research is encouraging self-determination and offering the participants a sense of autonomy, or if it removes their autonomy and puts the power with the researcher.

**Participatory approaches - issues of expertise**

The benefits of citizen science can be seen in projects conducted on a larger scale. Here, I refer to a project conducted by Macintyre which he refers to in his paper ‘Approaching Participatory Design in Citizen Science’ (2016). A pilot project, similar in nature to the proposed project of this dissertation, the participants engage in a citizen science based study and then feedback on how this made them feel. The participants within this study are elderly, a group which it could be argued fall within the ‘vulnerable adults’ category, similar to the learning disabilities community in terms of their marginalisation. They are both groups which require more support than other communities however, it is important to note here that this support is very different in each case. The findings clearly show that ‘the focus on participatory methods’
Macintyre, 2016: pg.9) gave the participants structure in which to challenge issues within their own lives, not just within the study. Macintyre (2016) suggests that questions were even raised about their own community. Early on within the paper, Macintyre presents what I argue is one of the major benefits of using citizen science with participatory design as a tool for engagement within marginalized groups. The participants ‘were also unfamiliar with the form of engagement, they were more familiar with adapting to what was being offered, sometimes consulted, not designing’ (pg.3). This clearly identifies two roles found within scientific engagement, the ‘expert’ and the ‘non-expert’. Within this dissertation I have referred often to the power relations between researcher/facilitator and participant. The expert is often seen as the researcher/facilitator as they are the ones with theoretical and background knowledge of what they are researching. The non-expert is the participant as they are seen as having a different scientific literacy, if any at all. Currently, there is a debate surrounding these terms, with the rise of the ‘amateur expert’ (Gura, 2013: pg.259). A combination of both the ‘non-expert’ and the ‘expert’ not necessarily specific to citizen science. Similarly, Leadbeater and Miller (2004) discuss the term ‘Pro-Am’, where professionals, in all professions are being replaced by people who could be classed as professional-amateurs. Macintyre’s (2016) study conveys how these roles have been drilled into citizens, so they only feel ‘consulted’ not allowing ownership of the work produced. Participatory methods allow for the ‘amateur expert’ to flourish and offers a supportive environment in which to allow them to explore. This break down of expert and non-expert roles allows for a more explorative process, not diminishing the role of the participant.

2.5 Conclusion
In summary, although plenty of research has been conducted in terms of citizen science, very little has been done into citizen inquiry. In the same vain there is little research or literature linking citizenship for people with learning disabilities to citizen science or inquiry. This is where my research sits, bringing an inclusive approach to an already established research technique, citizen inquiry and linking it to citizenship for people with learning disabilities.
3. Methods of data collection

This chapter discusses inclusive research as the methodological approach within this project. For this study six participants were recruited from the charity Yellow Submarine over five weeks. After an introductory session, I worked through a citizen inquiry project with the participants (topic selection and planning, data collection and data analysis) followed by a focus group in which the participants were asked about their views and opinions on the project and discussions were facilitated. Within this chapter I will discuss what inclusive research is and how it is used within this particular study. Furthermore, I will discuss my research paradigm and how that has affected the choices made within this project, including my choice of research methods. Finally I will examine the ethical dilemmas of the study and the trustworthiness of it.

3.1 Research approach – inclusive research

The three key research paradigms that can be found within the literature in relation to inclusive research are ‘participatory’, ‘emancipatory’ and ‘community/peer led research’ (Seale et al., 2014: pg.347). ‘Participatory’ research is defined by the involvement of the participants with the whole research process, treating them as fellow researchers. ‘Emancipatory’ research is defined by its focus on the empowerment of marginalized or ‘disadvantaged people’ (Kara, 2015: pg.45). ‘Community/peer led research’ is when communities are given the opportunity to steer the study and become agents in the way that the research is done. Bigby et al. (2014: pg.4) explain how the umbrella term ‘inclusive’ allowed ‘for diverse approaches and forms of involvement by people with intellectual disability’. It offers the researcher the ability to have a more open and flexible approach to their research, giving them the opportunity to use different research methods to best suit both the participants and the study. The main reason for using this research approach within my study is the opportunities and parameters it sets for working with people with learning disabilities. There are many different principles set out for inclusive research by different researchers. (Walmsley, 2004; Walmsley and Johnson, 2003; Stalker, 1998), however, there are common themes that run throughout.

The first is respect for the community within research. This is reflected in this project, as the participants are treated as equals. The second, is that the research agenda must always reflect their best interests and must be of interest to the community. Lastly, the research and any following documents, must represent their views and opinions truthfully. As an approach created solely for working with this group of people, its principles can be shown to be in the interest of the participants of the study.

As I identified in chapter one, there is a need for engaging people with learning disabilities with decision-making. Within the literature review I also discussed Morris’ (2005) three concepts of citizenship for people with learning disabilities. These echoed
the same sentiment, that there is a need to facilitate the space for people with learning disabilities to have their own voices heard. Inclusive research, ensures that a safe and supportive space is created in which the participants are treated both with respect and offered a platform on which to have their say.

Next, I will move on to discuss how inclusive research links to my research paradigm and what implications this has had on my study.

3.2 Research paradigm – critical theory, normalisation and participatory research

As discussed above, inclusive research covers different research paradigms. Within the literature, there is much discussion as to whether research can claim to be either ‘participatory’ or ‘emancipatory’. There is an argument that although studies may class themselves as one, they are in fact the other. This level of confusion has led to debate and demand that specific parameters be set out for each paradigm. Zarb (1992: pg.127-128) identifies two primary principles of emancipatory research; ‘empowerment’ and ‘reciprocity’, claiming that very little has been done within research ‘to contribute toward the empowerment of disabled people’. Furthermore, he identifies that research alone cannot directly offer empowerment. Participatory research is identified by Cocks and Cockram (1995) as a way of forming alliances between people with learning disabilities and non-disabled researchers. They also suggest that one key characteristic of participatory research is that both researcher and participant work together on a project to answer the research question. I agree that research may be defined more as ‘participatory’ or ‘emancipatory’, however there is also opportunity that from participation comes emancipation.

Walmsley (2001: pg.195) discusses the differences between these two research models, claiming that ‘participatory research is rooted in a long standing effort to co-opt and understand the ‘under-dog’’. She goes on to describe the emancipatory research paradigm stating that within this form of research ‘disabled people should have control, rather than merely participate in, the research process’. These two distinguishing features are both found within my research. Yet, the study aligns itself more with the participatory paradigm. The participants are constantly leading the discussion with the researcher reacting and adapting to their views, opinions and needs. With the main aim of the study being to understand their views and opinions, offering empowerment. It’s also important to acknowledge the fact that there are challenges to achieving this. The study is small and only offers this sense of empowerment for a small amount of time. Furthermore, without any support from the facilitator there’s always a chance that the participants will feel disempowered. This is where reflexive facilitation is important, the facilitator needs to be assessing their skills ensuring the participants are feeling empowered and effectively supported. This is why I have chosen to use the
participatory research paradigm, as this study facilitates both participation and engagement with the research. It also, facilitates engagement with research as a whole through the use of citizen inquiry and the scientific process of inquiry.

Often, within participatory research the question of ‘purpose’ arises. When using participatory research approaches, misuse can have harmful consequences for both participants and researcher. To address this we must first identify the purpose of the approach within the research. For this specific research study, my purpose is to create a safe and inclusive environment in which views and opinions aren’t judged but are unpacked and valued, in order to create an alliance between the researcher and participants that allows for participation on any level within the research.

Participatory research can be influenced by normalisation theory. Walmsley (2001: pg. 190-192) explains how the theory ‘draws on both human rights and on deviance theory’. Normalisation was a theory created by academics without learning disabilities and takes responsibility for change away from the community of people with learning disabilities. However, it does need the community to adapt ‘so that they can become carriers of positive social identities’. It puts an emphasis on the importance of equal and ‘valued social roles’ similar to inclusive research. Wolfensberger (1982: pg.136) is a key researcher associated with this theory and the application of it to the learning disabled community. He discusses how there are seven core themes in normalization theory. Here, I would like to point out one which I believe shows an impact of normalization theory on this study; ‘the importance of social integration and valued social participation’. He talks about the negative effects of segregation on both the community and society as a whole, and how normalization attempts to redress these. He places emphasis on removing segregation which is what links this study to normalization theory. It looks at breaking down power relations and ensuring that the views and opinions of the participants are valued just as highly as the researchers.

Similarly, critical theory is described by Cohen, Manion and Morrison (2000: pg.28) as aiming ‘to realize a society that is based on equality and democracy for all its members’. They later claim that critical theory identifies the issues in ‘consciousness that has brought an individual or social group to relative powerlessness’. In a later edition of the same book, Cohen et al. (2013: pg.37) link participatory research and critical theory explaining how participatory research is ‘an instance of critical theory’. This idea of ‘powerlessness’ embodies what my research study and general practices are about. Disability studies are often focused on the empowerment or participation of people with disabilities, removing this idea of ‘powerlessness’ and sharing power between communities.
3.3 Research methods – ethnographically informed observation and focus groups

Within this study I employ two different research methods; ethnographic approaches to observation and a focus group. I will discuss the different methods in turn and talk about how they are employed in this study.

*Ethnographically-informed observation*

Within ethnography, observation is a popular way in which to collect data. Hammersley (2007: pg.99) argues that the ‘naturally occurring’ and ‘unsolicited oral accounts’ may provide the ethnographer a source of ‘both direct information about the setting and of evidence about the perspectives, concerns and discursive practices of the people who produce them’. This source of information provides the ethnographers with a deeper insight into the social phenomena they are studying through the views and perspectives of the people affected by it. Within this study, it could be argued, that my research introduces interventions due to the facilitator role within the project itself.

In this project, I chose to adopt ethnographically-informed observation as it allows for a more participatory approach with the participants. I argue that what I use in this project is not ‘pure ethnography’, as I often had to facilitate and intervene within the sessions, therefore choosing to adopt the term ethnographically-informed observation. Furthermore, because of the role I had to take on within the project, I argue that whilst influenced by ethnography I adapted to the situation meaning I could not take on a specific role such as ‘complete participant’ (Hammersley and Atkinson, 2007: pg.85).

Within this project, I adopted the participant role by immersing myself within the social club community in which the research takes place by volunteering for the rest of the club sessions. This allowed for a better relationship to form between myself and the participants. I fulfilled the observer role by taking notes and/or recording during the sessions, offering opportunities for the participants to interact with one another and facilitating and supporting these within the environment. I recorded their interactions with both the activity, and with one another. Additionally I took on the role of facilitator, straying from the typical form of observations found in ethnography.

*Focus groups and participatory exercises*

For the final session of the project, a focus group provided opportunities for the participants to share their opinions and views on citizen science. Focus groups are described by Kitzinger and Barbour (1999: pg.4) as ‘group discussions exploring a specific set of issues’ highlighting the importance of group interaction. I facilitated the exercise, creating a safe and open space in which the participants could discuss their views and opinions, focusing on a set of questions which I had scripted prior to the session. Cambridge and McCarthy (2001) explain the benefits of using focus groups:
1. ‘Help people to gain confidence in a group environment’.
2. ‘Create safe, non-threatening and non-intimidating environments for user organisation and discussion’.
3. ‘Provide for inter-member reinforcement, peer support and validation of views and experiences’.
4. ‘Enable members to participate in research from which they would otherwise be excluded due to poor literacy skills’.

These four benefits and opportunities described by Cambridge and McCarthy are specific to people with learning disabilities and outline the main reasons as to why I used this approach. I would argue, however, that these four benefits and opportunities need to be adapted in relation to the context of any research project. For example, the first benefit did not apply to this group as they were already confident within a group environment. Instead, it was my responsibility, as the facilitator, to manage the group dynamics, by making sure everyone has their say. I also believe that participatory methods allowed for this form of facilitation.

3.4 Ethics
During the planning stage of this project three key ethical issues were identified:

1. Working with vulnerable adults
2. Addressing the issue of power
3. Informed consent

I will address each one of these in turn, unpacking the issues and how they were dealt within this research study.

Before beginning the study I sought ethical approval from the Human Research Ethics Committee (HREC) and was granted approval on 19/04/17 under the reference: HREC/2017/2497/Carr/1 (Appendix A). Since approval only the title has changed, through more extensive reviewing of the literature.

Working with vulnerable adults

One of the key ethical issues was the ‘vulnerable’ status of the participants and their overall safety within the study. The study itself was ‘opt-in’ where the participants have the choice to join the project. Similarly, they were told they were allowed to exit the study at any point. They were encouraged to participate however much or little they wanted too. On more than one occasion participants chose to opt out of one or two sessions, due to personal preferences. They were ensured that this was allowed and upon their return to the sessions they were informed of what had happened previously.
Safeguarding is the most common issue when working with vulnerable people. I addressed this by following Yellow Submarine’s safeguarding procedures and ensuring that anything that was disclosed to me was passed on to the relevant staff member immediately. When working at Yellow Submarine, I had undertaken safeguarding training both internally and externally. This meant I understood the procedures for safeguarding the participants.

**Informed consent**

The study worked directly with vulnerable adults therefore informed consent had to be gained before participants could embark on the study. The consent forms were given to the possible participants in the original session and they were told they could either sign it themselves or seek consent from their parents or guardians. As they are adults, it was important to not remove their ability to make the decision to participate by themselves. Furthermore, when they requested that they wanted to sign up to the project, I talked through the consent form with each individual separately. If they wished to sign it themselves, then they were told throughout the process that consent is their choice and should they wish to leave the project then they will not be forced to continue, instead they will be supported in their decision by both myself and by the activity leader at Yellow Submarine. With two of the participants, they consented after having previously joined in on a session as they were waiting for their parents to give them their consent forms. The participant and parents were informed that potential data collected from these participants would not be used unless consent was given.

One participant originally identified that they wanted to join the project, however, at the next session their guardian explained how the participant then chose to opt out. The guardian expressed that they believed this wasn’t the sort of thing they would enjoy, and that perhaps they wouldn’t give a high level of engagement.

**Addressing the issue of power**

As discussed earlier on in the dissertation, in relation to participatory approaches, the world we live in is based on a hierarchical system, in which those with more money, more knowledge or more skill are given more power and those who belong to marginalised and stigmatised communities have power taken away from them. Within this study, I was keen to ensure this was addressed using a reflexive practice to ensure this. As someone without a learning disability it was important to me that I didn’t use this privileged position to gain the results I needed and to remove this position of power. For example, I created a context which encouraged the participants to take control over the citizen inquiry project. Having worked for Yellow Submarine in the past, I believe this gave me an advantage as many of the participants knew me prior to
signing up for the project, giving me a more ‘insider’ position. As Hammersley and Atkinson (2007) explain, ‘those defined as outsiders or insiders are likely to have immediate access to different sorts of information’ (pg.87). In this scenario being an insider allowed me to facilitate participatory approaches as the participants were already aware of who I was.
4. Collecting and analysing the data

In this chapter I will first look at the collection process, what methods were used and any challenges faced through the use of these methods. Secondly, I consider the analysis process discussing thematic analysis and presenting the initial themes and codes.

4.1 Collecting the data

Within this study, two forms of data collection methods were applied. The first was fieldnotes, where as an observer and facilitator I took notes on actions and phrases that came up within the sessions. The second was audio recording and transcription, where transcription took place soon after the sessions. I will discuss each of these in turn, mentioning any positive outcomes alongside any challenges I faced through the use of these methods.

Fieldnotes

For the first two data collection sessions, field notes were used as the sole method to collect the data. During these sessions, I identified more of a need for facilitation than I had previously thought, meaning fieldnotes had to be written post session. Hammersley and Atkinson (2007: pg.142-144) state that whilst ‘note-taking is not always possible or easy even in overt research’ the researcher ‘should aim to make notes as soon as possible after the observed action’. This shows, that although writing up fieldnotes post-session is a challenge it is not uncommon. Furthermore, Hammersley and Atkinson discuss how adequate time must be put aside for the writing of fieldnotes. Within this study, the social group was set up so that after my sessions were done, I could retreat and write up my notes almost immediately allowing for more information to be recorded. In order to ensure that data was not missed, in the third session I also used a voice recorder and transcribed the recording post session.

Hammersley (2007: pg.142) explains that ‘field notes are always selective’. This suited the project as I did not want to use intrusive methods to collect the data, as I believe it could have influenced both the participants and the power dynamic. It also allowed me, as an observer to be more interactive with the participants only noting down instances of particular relevance. Furthermore, it removed the need for more research instruments, which in turn could distract the participants from engaging within the sessions.

Prior to the fieldwork, I prepared two templates for fieldnotes. Appendix B was a very basic template which I could use during the sessions to write notes, with spaces for any important quotes or actions with a section to write timings down to jog my memory later on. This was then translated post session into ‘proper’ fieldnotes on Appendix C. This
was a much more detailed template focusing on the types of support identified within the session, with spaces to note down anything else of importance from the session. I chose to use two templates to ensure that my notes were structured and organised and to make writing up and analysis easier.

During this project I utilised both the Sense-it application and the nQuire-it platform (www.nquire-it.org) with the participants, engaging in a project of their choice. The nQuire-it platform is a citizen inquiry platform which offers the user the ability to create and join scientific ‘missions’. It hosts missions of three types: ‘win it’ in which a challenge is set with prizes, ‘spot it’ focused on the collection of images and ‘sense it’ where users can use the Sense-it application to collect data and share it using their mobile phone sensors (nQuire, n.d). The participants chose to look at the noise levels within different places in Oxford to find out where was the loudest. I believe, they chose this topic as one of the participants was complaining about the level of noise in the room. This then prompted a discussion about the noise levels in different places in Oxford. During the data collection sessions, I facilitated short sessions in which the platform and app were introduced and then the method of data collection (identify a topic, collect the data, analyse the data) was performed with the participants leading.

After, the participants had identified a topic they wanted to research and Participant 1 wrote up a short introduction on the nQuire-it online platform, explaining what the mission was aiming to achieve (See Appendix F).

In the second session, we used the Sense-it app to collect our data on both phones/tablets provided by myself and their own phones. This was where the first problem with the application was discovered. None of the technology would connect the application to the online platform. Data was then collected just on the app without linking to the mission on the platform. This became an issue during the data analysis session, when the participants had to look at the data sets in turn on the Sense-it app instead of having it applied to their mission. However, we followed a similar structure to the platform with participants commenting on each other’s data sets and coming to a conclusion as a group (See Appendix G).

**Focus group – audio recording and transcription**

For the final session, I facilitated a focus group with questions that had arisen from the previous four sessions. The aim of this session was to discuss the participants’ views of the project. Prior to beginning the project I wrote a script (Appendix D) for the focus group, however I adapted this script to take account out evolving issues (Appendix E).

One issue with audio recording was identified prior to commencement of the project. This is linked to communication difficulties, however this was rarely an issue with only
one participant having difficulty with communication. This issue was addressed by offering the participant opportunities to talk or write down what they wanted to say, however they also didn’t like writing. They were often overshadowed by other participants, meaning more facilitation within sessions was required to ensure they had the opportunity to talk if they wanted to. I chose to do this by ensuring that I asked each participant for their opinion in turn during discussions. Furthermore, I used flipchart paper in order to allow participants to engage with the discussion through writing if they chose not to speak, and the tablets and phones had note-taking apps on them should they wish to use those also. Another method I used was having happy, sad, confused and bored faces printed out should the participants wish to engage using those.

4.2 Analysis of the data

Thematic analysis

Thematic analysis is described by Braun and Clarke (2006: pg.78-79) as ‘a method for identifying, analysing and reporting patterns (themes) within data’ which ‘minimally organizes and describes your data set in (rich) detail’. It allows the researcher to interact with their data in a hands-on manner, identifying codes and themes through the reading and re-reading of their data. It is thought to be a ‘flexible’ method through its ‘theoretical freedom’ allowing the researcher space to make decisions without being tied to one particular theory or epistemological view.

I used thematic analysis approach, as I believed it aligned most closely to my objectives. Braun and Clarke (2006: pg.82) suggest that prior to engaging in thematic analysis, the reader should make decisions about how they are going to progress with the analysis. Here, I would like to describe the decisions I made before analysis following the decisions Braun and Clarke (2006) describe:

1 – Defining themes:

Using my analytical framework identified in chapter one (Box 1.) I used the three themes identified that guided my study; community, engagement and support, and this is how I structured my fieldwork and I believed this would be conveyed within the data. I also added a fourth theme when doing the analysis; identity.

2 – Type of analysis:

Given the qualitative nature of the data collected I decided to do a ‘rich thematic description’ as described by Braun and Clarke (2006: pg.83).

3 – Identification of themes:

To begin with I coded the data in a ‘theoretical’ (Braun and Clarke, 2006: pg.84) manner, with a pre-existing coding frame (the three themes already identified).
Furthermore I chose to use both an inductive and deductive approach, first using the three themes within my analytical framework as themes within the analysis. Later, I analysed the data by looking at it without these themes in mind, instead detecting patterns that came from the data. This is how I identified the fourth theme, identity.

4 – Levels of themes:

For this study, I analysed the data with a ‘semantic approach’ (Braun and Clarke, 2006: pg.84) choosing not to interpret what the participants have said, instead just looking at the ‘explicit or surface meanings’ of what they have said. This was mainly due to representation. As an ‘expert’ I didn’t think it was appropriate to attempt to interpret the participant’s words and phrases as I believe this removes the participants ownership over the data.

Another decision I made was how to analyse the data, manually or by using CAQDAS (Computer Assisted Qualitative Data Analysis Software). I began to analyse manually, however decided this meant that I was missing key themes. I then moved onto the CAQDAS ‘Dedoose’ which made the coding of the data easier giving me the opportunity to look more in depth at the data.

Analysis of the data

In Appendix H I show the initial analysis of the fieldnote data. This data includes not only my fieldnotes but also research journal entries. These were written to support the fieldnotes and flesh out some of my ideas that occurred during the sessions that weren’t appropriate for the fieldnotes.

As mentioned earlier, my fieldnotes were targeted at noting down events or words relating to the support theme. The analysis shows how the research journal entries allowed for a much broader analysis, looking at all of the themes.

In Appendix I, I work through the initial analysis of the transcript data. The four themes identified within the data and their codes can be seen in Table 1 below.
Table 1. Themes and coding

<table>
<thead>
<tr>
<th>Theme</th>
<th>Community</th>
<th>Engagement</th>
<th>Support</th>
<th>Identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Code</td>
<td>Previous experiences with science</td>
<td>Enjoyment</td>
<td>Peer support</td>
<td>Independence</td>
</tr>
<tr>
<td></td>
<td>Opinions of science</td>
<td>Technology</td>
<td>Facilitator support</td>
<td>Friendships</td>
</tr>
<tr>
<td></td>
<td>Understanding of citizen inquiry</td>
<td>Distraction</td>
<td>Collaboration</td>
<td>Decision Making</td>
</tr>
<tr>
<td></td>
<td>Inquiry process</td>
<td>Technology</td>
<td>Scientific Literacy</td>
<td></td>
</tr>
</tbody>
</table>
5. Interpreting the Data

In order to ensure that interpretations are of value, they should be situated within current arguments and knowledge surrounding the subject area. First, I will give a brief explanation of each session in order for the data and my interpretations of it to make sense in context. Next, I break down my data looking at it through the four themes identified. I discuss what I believe the data means, the importance of it and any alternative explanations. Finally, I discuss my interpretations in relation to the wider context of both inclusive research and citizen inquiry.

5.1 Session explanation

In order to give context to my following interpretations I will first introduce each session, explaining what happened in the sessions.

Session 1 – Introductory session

The first session was brief. I spoke to the members of the social group separately, describing the study and what was involved. I offered it up to questions and then spoke to those who had expressed interest. At this point consent forms were handed out and when parents/guardians came to collect the members the study and consent forms were discussed with them.

Session 2 – Topic choice

The second session began with a check in, where the participants discussed how they were feeling and shared anything they wished to share with the group, to enable the group to bond with one another. We then moved on to picking a name for the group and a topic to study and collect data for in the next session. They decided as a group to look at the loudest places in Oxford using the Sense-it app to record data on the noise levels. We also spoke in more detail about the particulars of the study; location, length of recording. One participant then volunteered to write up the project on the nQuire-it website, making it public.

Session 3 – Data collection

This session focused on collecting the data using the tablets and phones provided. As a group, we went out and picked five different locations to record data. The participants then chose how long to record in each location. The session finished with a short debrief, in the final location where we discussed as a group what we had done.

Session 4 – Data analysis

The fourth session was focused on analysing the data. We began by discussing what analysis is and how we wanted to analyse our data as a group. The participants then
began to analyse their data with support from me, finishing the session with findings. The participants came to an agreement based on their analysis of the data.

**Session 5 – Focus Group**

The final session was a focus group, which I had scripted questions for prior to the session based on the previous sessions. The group were encouraged to discuss and also to answer the questions.

### 5.2 Community

The community theme focuses mainly on how the participants understand citizen inquiry. I believe this understanding is made up of both previous experiences with science and their current and past opinions on science. I did identify that although many of the participants had previously had negative experiences with science, this didn’t necessarily affect their current opinions on science and therefore their understanding of citizen inquiry.

**Previous experience with science:**

‘P5 – Do you know what I actually didn’t like science at school cus all we were doing was writing and it was sort of boring

JC – So what do you like about it?

P5 – The worst do you know what can I tell you the truth? The worse thing that I’ve done at school is is dissected a pigs bladder’

**Session 5 – Focus Group**

**Current opinion on science:**

‘P5– I love science I love I love the prospects of science I would say

JC – OK what do you mean by the prospects of science?

P5 – Like how it how it like all fits together how like basically the way of the world’

**Session 5 – Focus Group**

The same participant (P5) appeared originally to understand citizen inquiry completely separately to science:

‘P5 – I wouldn’t consider that science I’d just consider it an experiment’

**Session 3 – Data collection**

Overall the participants understood citizen inquiry in a positive way:

‘P5 – One word I that I also hope I would want to say legendary

JC – Legendary awesome (P4)

P4 – World-class

JC – World-class like it (P2)

P2 – Professional
Each of these descriptions show an overall positive understanding of citizen inquiry. One possible interpretation would be that the participants understood the link to science and the professional role they took on in the project, also expressing that this was an enjoyable experience for them.

**5.3 Support**

The third theme, support, looked at the levels and types of support required to facilitate engagement for the participants. Through analysis I was able to identify four types of support for this project: Peer support, facilitator support, technology support and collaborative work. Each of these helped the participants to engage with the study, facilitating the opportunity to work inclusively as a group.

‘P1 – I’ll tell you something, I love every moment of this project
JC – Ok and what did you enjoy the most?
P1 – Most likely introducing to you and all the people in the group’

When planning this study, the literature suggested the best way of doing this was to use inclusive approaches. I believe the data supports this. Firstly I believe that both peer support and the opportunity to collaborate were key in engagement for the participants.

‘supported by others in the room, and the ideas came out of this – One participant straight after said we could research pubs and how loud they were – in reaction to participant [6’s] comment. All were very supportive of the participant who didn’t like shouting by lowering their voices’

The group used each other’s likes and dislikes, to inform their choices for subject topic. However, the group did identify that they would have preferred to have worked with people they did not know.
'JC – And did you enjoy working with your friends or do you would you have preferred working with people that you didn’t know?

P4 – Didn’t know
P5 – Prefer to get to know people
JC – People?
P3 – Didn’t know’

Session 5 – Focus Group

Alongside this they mentioned that they wanted to work in smaller groups, however they couldn’t give an explanation for this.

‘JC – So do you reckon you enjoyed working in a big group or do you reckon you would have preferred to have done in a on your own or in a smaller group

P3 – A smaller group
P1 – I would have done it I would have done it by partners but in a in a smaller group

JC – Why why so (P3) why would you have preferred to have done this in a smaller group. Or do you you not sure

P3 – Not sure’

Session 5 – Focus Group

Often the group dynamics were linked to what was happening outside the project, more specifically friendships and family issues. Navigating these issues required more support from the facilitator. For example, the desire to work with new people may have been due to issues with friendships, which meant that some of the participants within the study weren’t getting on, putting a strain on the group dynamic. The levels of facilitation required were often more than expected.

‘Only facilitation needed was to structure the session and to make sure all voices were heard – in particular one participant who only speaks up when upset or when questioned.’

Session 2 – Topic Choice

Within my fieldnotes I documented a need for need for minimal facilitation however, when reflecting after the sessions this was not the case.

The technology used, the Sense-It App and nQuire-It online platform, often required a lot of support to begin with. The participants needed help with creating their mission online.

‘Once dinner had been eaten, one participant created the mission on nQuire with a large amount of support from me (technology wise and spelling wise). They were very proud of it and that other people could see it’.

Session 2 – Topic Choice
This was due to the lack of instruction offered on the website. Similarly they struggled with the Sense-It app to start with, however once they had been shown how to use it a few times they appeared to need less and less support.

'The participants still needed some support with the recording function on the tech.'

'All participants needed support with the technology, being shown how to record.'

Session 3 – Data Collection

Overall, the participants required support on all levels, more than I had previously identified when planning the study. The technology was not accessible enough as it didn't have obvious instructions for people struggling with using it. Furthermore, the peer support appeared to effect other aspects of the support required. It enabled them to support one another with the technology, with participants who struggled being helped by those who understood it. They would also support each other with tasks such as spelling, when writing as a group. However, there was still support needed from the facilitator. I argue that this had a little to do with the research element that I was still seen as the expert and therefore I was the person they turned to instead of attempting to work things out on their own or turn to their peers for support.

5.4 Engagement

The engagement theme was originally targeted at looking at how the participants engaged with the technology, however through the analysis of the data this adapted to include their engagement within the study as a whole. Through this analysis I identified how distractions affected both engagement and enjoyment within the study. I also identified how many of the participants engaged not only with the technology but also with the inquiry process.

'JC – OK now this is a big question now that you’ve done the project do you feel like you’re actually researchers?

P1 – Yeah

P5 – You know what I came prepared for that question

JC – Did you?

P5 – I did

JC – OK

P4 – 100% yeah

JC – Yeah?

P2 – Yeah cus I got a phone
P5 – Can I tell you a secret though?
JC – Of course you can tell me
P5 – I feel like I’ve been a researcher my whole life’

Session 5 – Focus Group

The inquiry process allowed for the participants to engage with their data, perhaps facilitated by the technology. In the extract below the participants are discussing their findings from the analysis of their data, in particular they are discussing two measurements one from the road and one from a bar (The Lighthouse).

‘P5– The road was up to was road the second one?
JC – Yeah road was the second one so what did that go up to?
P5– We didn’t record it long enough
JC – I think (P4)’s went up to 83
P1 – The loudest
JC – OK so what we going for as our loudest?
P5– Probably the road
JC – OK and why do we think it’s the road?
(mumbling)
JC – so you think it’s the road from the bar that’s telling us how loud it was
P5– I think we have to put the quietest as The Lighthouse probably cus there was like hardly anyone in there’

Session 4 – Data Analysis

One participant (P3) chose not to join in on the data collection session due to their romantic partner being present at the charities social group. As they do not have the chance to spend time together away from the social group, P3 decided to spend time with them instead of joining in with the session. The same participant was also very easily distracted during the sessions.

‘One member was more concentrated on next task (playing football) – didn’t seem to engage in the project’

Session 4 – Data Analysis

The group required facilitation, in order to ensure distractions weren’t hindering their engagement in the project. However, it was important this was managed correctly in order to ensure that I wasn’t enforcing an ‘expert’ role and forcing the participant’s to engage unwillingly.

The technology also encouraged the participants to engage in the inquiry process. It offered a system in which the participants could collect their data and analyse it without the need of an ‘expert’ to do it for them.
‘JC – So we’ve got a little bit of a difference so we go from 78-83 so what do you think the differences might be if we were doing the road the difference in sound if we’re stood on the side of the road

P4 – How many cars passing by

JC – Cars passing by but why do you think yours and (P5)’s are different as to the loudest sound?

P5 – Umm cus we probably recorded it for less time

JC – OK so we did it for less time yeah

P5 – We did ours for like eleven seconds’

Session 4 – Data Analysis

The participants were able to look at their data and make their own judgements on analysis. As mentioned earlier, the technology did not work properly as it wouldn’t connect the application to the online platform. However, the participants made the decision to analyse their data by hand as opposed to using the platform to analyse it for them.

The participants appeared to enjoy using the Sense-It app and one participant (P1) said that they would like to continue to use it.

‘JC - what did you think to the app that you download that we used

P1 – You know what? It’s absolutely fantastic

JC – You enjoyed it OK

P1 – You know what I’m gonna keep that app

JC – You’re gonna keep it

P1 - Cus I wanna use it

JC – OK that’s cool and what do you think you’ll do with it do more?

P1 – I’ll use it at Gap I’ll see how uhh the noise is levelled at Gap is and then I’ll let you know’

Session 5 – Focus Group

The technology enabled the participants to engage in the inquiry process, offering them a platform on which they could record, store and analyse their data. It also offered them the opportunity to share their work with others. The data showed that the participants, although occasionally needing support with the technology engaged with it and enjoyed using it.

5.5 Identity

The final theme of identity was introduced during the analysis. I argue that this theme helps to explore how the participants understand citizen inquiry, as they are agents of their own engagement. I believe their engagement is affected by how independent they are and similarly the way in which they create and manage friendships. Furthermore,
within this specific study, their identity appeared to be affected by their ability and want to make decisions and their level of scientific literacy before entering the project.

‘P5 – I feel like I’ve been a researcher my whole life
JC – I like that that’s a cool little phrase
P5 – Seriously I do I literally every day when I get the chance I go to look for stuff and I research on it’

Session 5 – Focus Group

The participants appeared to identify as citizens both through being independent people and also through the friendships they developed within the group. These enabled the participants to work together as a group, whilst still understanding the importance of working on their own. They would employ these skills when making decisions, whether it be independent decision making or doing it as a group. The participants were encouraged to make all the important decisions within the study, with minimal support.

‘P5– It makes sense to it also makes sense to do it by hand cus doing it doing it on the tablets it’s not really something might happen with the iPads
JC – Yeah
P5– We might lose our data
JC – So
P5– So it makes sense to do it by hand’

Session 4 – Data Analysis

Other participants showed independence through the inquiry process. Through their decision making they became independent agents influencing their own research, essentially they all became researchers.

‘In here four of the five participants went off on their own with P6 following them shortly after.’

Session 3 – Data Collection

Furthermore, they identified that as a group they would like to run a similar project with their peers at Yellow Submarine. This shows a large amount of independence and confidence in their ability to present what they have done. This reflects the amount of support given and how the participants felt they had been supported enough throughout the project to lead the next one. Arguably this could be seen as ‘training the trainer’ and that I, as a facilitator, was just training the participants to take on the responsibility of facilitator for the future. This relates back to Morris’ (2005) concept of ‘self-determination’ and that I, in the situation of this study, was someone with power. Through the inclusive methods employed the participants felt empowered enough to claim they would like to take on the responsibilities as well.
The participant’s scientific literacy appeared to affect the way in which they understand certain scientific terms. Within the group, most of the participants could relate the terms being used in our sessions to their own personal interests making it easier for them to understand.

‘JC – So what sort of analysis do you think they do in football?
P4 – Like goals and like penalties and
(mumbled speech from other participants in the background)
JC – OK so you think they’re analysing what are they analysing
P4 – Analysing basically goals and um
P5 – Do it in a minute
P4 – So basically half time and full time
JC – Oh wow ok
P4 – So what they do they decide like goals and uh like uh like penalties and fouls and uh offsides’

Session 4 – Data Analysis

Here, one participant identified with analysis through football statistics, whereas another participant was able to relay scientific definitions, in their own words, as they had watched a science based television show.

‘P5 – I know what a hypothesis is
JC – Go tell us (P5)
P5 – I watch big bang theory
JC – Ahh so we’ve got our own little scientist here
P5 – So basically a hypothesis is something that you’re not sure of but you think you’ve got an idea of what it is’

Session 4 – Data Analysis

Each of these contributed to the way in which the participants identified themselves, and equally how they identified themselves in the world of science. Over the period of the study, people’s perceptions of themselves changed, with more people claiming they liked science.

5.6 Discussion

Firstly, I would like to discuss this project and its relation to inclusive research. The data show how inclusive methods allowed for the participants to engage with their data and the project as a whole. Previously I argued for the importance of inclusive research citing Walmsley and Johnson’s (2003) three principles. Here I would like to discuss these three principles through the data and the analysis. The first principle looks at addressing issues that are of importance to people with learning disabilities, and leading to ‘improved lives’. The participants within this study showed a clear sense of
independence and decision making skills, deciding on a topic which they were interested in researching and they believed to be important to them.

‘One participant (P6) didn’t like the loud talking so covered their ears and asked everyone to stop. This prompted conversation about sound with one participant (P3) suggesting we look at pubs, followed up by another participant suggesting we look at how busy they were.’

Session 2 – Topic Choice

There were opportunities here for the study to lead to improved lives for the participants not only through the identification of the nosiest places in Oxford, but also through the opportunity to be independent and have autonomy over the project.

The second principle looks at the way in which the participants are treated by the research community. I argue that the participants felt respected with one participant identifying that they already felt like a researcher. I believe this shows that they don’t feel excluded from this section of society, and that this came out of the opportunity within this study to become the experts removing the barriers previously put in place.

Finally, the third principle focuses on the idea that the research itself ‘must access and represent their views and experiences’ (Walmsley and Johnson, 2003: pg.16). I believe this study focuses on answering questions related to the participants’ views and experiences, and that the interpretations of the data are made without adapting these. The data is used to inform my interpretations and at no point is it misrepresented. I argue that it is clear that inclusive research allowed for the participants to engage in this study and had a positive effect on their overall view of citizen inquiry and more generally, science.

Next I discuss where this research and its findings sit within the current literature and citizen inquiry. As identified in the literature review, there is not much literature focused on citizen inquiry. What there is discusses how it aims to offer ‘supportive communities’ in which people can use ‘authentic science practices’ to research topics of relation and importance to themselves. (Villasclaras-Fernandez et al., 2013: pg.383). I argue that the data found under the support theme illustrates how the participants created this ‘supportive community’ choosing to identify as a group.

‘“Team” – term used often by many of the participants’

‘Name of the group = “just do it – as a group”

Session 2 – Topic Choice

Furthermore the inquiry process offered by citizen inquiry and facilitated by the nQuire-It platform and Sense-It app, encouraged participants to engage. The data suggests that citizen inquiry has the potential to offer opportunities to break down barriers and for
the participants to engage in positive science practices readdressing their previous views and opinions of science.

The study itself was aimed at discovering how people with learning disabilities understand citizen inquiry. I argue that they understand it through all four of the themes identified. Firstly, they understand it through the scientific community, identifying the professional nature of science. The study offered the participants a chance to change their views and engage in scientific inquiry relating to their experiences. Secondly, they understand it via the support they are given. This was shown through their positive descriptions of citizen inquiry e.g. ‘legendary’. As discussed above, citizen inquiry is based on ‘supportive communities’, but these need to be facilitated and managed through resources such as technology and peer support, whilst still allowing the participants to explore independently. Thirdly, the way in which the participants engage with the process informs their understanding and opinion of citizen inquiry. Depending on which part of the process they engage with more, they will understand citizen inquiry differently. The participants are agents with free will over how they wish to engage with something. Within this study, their identity affected their engagement and their overall understanding of citizen inquiry.
6. Findings

6.1 Assessment of findings
This study had three research questions:

1. What do people with learning disabilities understand by citizen inquiry?
2. What forms of support are required for citizen inquiry projects when working with people with learning disabilities?
3. Does the nQuire-it platform support engagement for people with learning disabilities?

It was influenced by an analytical framework (Box 1) that I developed in response to gaps which I identified within the literature.

The first research question set out to understand what people with learning disabilities understand by citizen inquiry and what factors influence their understanding. Box 2 below displays two different understandings of citizen inquiry. The first is what a citizen is, e.g. scientific and professional. The second is their personal opinions on citizen inquiry, e.g. awesome and legendary. These two ways of understanding create an overall positive view of citizen inquiry. Although these give us only a small amount of data to work with, and more research is needed to expand and define these understandings, the data shows that the participants understood citizen inquiry through how they defined a citizen and how the project made them feel. The negative experiences which all participants had, came mainly from previous experiences. However, citizen inquiry helped to reframe their views on science and offered them an opportunity to engage in scientific inquiry in relation to their personal interests. Identity then, plays a large part not only in their understanding of citizen inquiry, but also their citizenship on the whole. Morris (2005) discusses three concepts of citizenship, yet I argue there are more than just three with identity being one of them.
Box 2. Citizen Inquiry – as understood by the participants

The participant’s engagement in the study also helped to frame their understanding of citizen inquiry, with many of them being affected by external factors within their own lives. This enabled them to understand parts of the inquiry process through relating it to their own interests but also created distractions within the group creating a need for more support. The inquiry process itself offered opportunities for the participants to engage by giving them autonomy with their research.

This leads onto the second research question, which looked at the different levels of support required when working with people with learning disabilities. The participants identified a need for more support with the nQuire-It platform and related mobile applications. However, the applications did engage all the participants in the inquiry process even those who would often disengage from discussions.

The participant’s identified a need for smaller groups, and a wish to work with people they did not already know. This illustrates a need for facilitator scaffold in order to support the group dynamics. It also highlights a need for peer support as the participants did still identify a wish to be in a group. Furthermore, they also claimed that they would like to run a similar project with their peers taking on the facilitator role themselves, showing not only an interest in citizen inquiry but also a level of autonomy for the participants.

The analytical framework introduced in chapter one (Box 1.) guided the project, but also helped to unpack the data. Each theme was clear within the data, and identified a
need for researchers to engage with and be inclusive of these within their work with people with learning disabilities. Furthermore, a fourth theme was discovered through analysis of the data which I argue should be added to the framework to guide future projects similar to these.

**Box 3. Analytical framework – post data analysis**

![Analytical framework diagram](image)

This framework applies to three key issues I have identified and addressed through this project. Firstly that people with learning disabilities can do citizen inquiry. They showed an interest in the process and studied a topic which related to their community. Secondly, all citizens should have the right to engage this way. This study showed that this group could engage when given the opportunity. Thirdly, that all citizens should be supported as required to engage. The forms of support offered in this study facilitated an environment in which the participants felt they could engage.

Finally, within the literature I identified a need for opportunities to allow decision-making within the learning disabled community. Linking back to Morris’ (2005) concept of ‘self-determination’ I believe that this study facilitated a space in which the participants felt autonomy in their decisions. Inclusive research and citizen inquiry allowed for this space to be created. Whilst support was still required the participants made their own choices throughout the study meaning that the project was their own.

P5 – Can I tell you a secret though?
JC – Of course you can tell me
P5 – I feel like I’ve been a researcher my whole life’

**Session 5 – Focus Group**

This quote identifies how the participants were given a platform on which to discover their autonomy and create scientific identities for themselves through their decision-making.

**6.2 Limitations of the study**

This project had a number of limitations. The main methodological limitation of this study was the focus group. Whilst this method is more inclusive than interviews, it
limited the amount of data I was able to collect. Furthermore, the participants often used it as an opportunity to disengage from the discussions which created facilitation issues. I think an alternative method could be one-to-one interviews with an opportunity to have a facilitated discussion after the interviews, so the participants could discuss their opinions.

Another limitation of the study was time constraints. Due to the set-up of the social group we were often given much less time than originally anticipated. I would often use the check-in time and some of the time of the first activity if necessary to conduct my sessions. The real time constraint was the participants needing to go out for food just over an hour after the social group began. This meant less data was collected and de-briefs had to be cut short to allow the participants an opportunity to re-join their peers for the social group. If the study were allowed more time, it might create more interesting discussions in the de-briefing sessions and allow for the participants to have more freedom with their engagement in the inquiry process. Ideally, each session would allow a full hour with time for an adequate debrief at the end of each session.

Furthermore, the data collection methods needed to be adapted. Due to amount of facilitation support needed, fieldnotes had to be written up post-session. In future studies of a similar kind, audio recording each session would ensure that less data was missed, and would offer supporting data for the fieldnotes.

These limitations are methodological in nature, however I identified one further limitation. I believe that whilst I have experience working with this group, it was a new context for both myself and the participants. The facilitator for studies of this nature, needs to be confident in both their setting and their objectives for the research. Equally, it could be helpful to have more than one facilitator with both facilitators engaging with the sessions and supporting in different ways for example, one facilitator supporting the participants individually and the other supporting the group as a whole.

6.3 Future Work
Research into citizen inquiry is an emerging field, and I believe this study offers opportunity for future research into this area. Through this study I identified how one small group of participants understood citizen inquiry and what levels of support they required to enable their engagement. This study could be adapted and replicated with more groups of people with learning disabilities. Furthermore, introducing the idea of facilitators with learning disabilities would remove some of the methodological challenges and ensure that the research is more inclusive in nature.

As discussed above, the analytical framework identified in Box 3 proved to guide the process in an inclusive manner and also to help answer the research questions. I argue, that this framework could inform science communicators about how best to work
with people with learning disabilities. In order to confirm this, further research needs to be undertaken.
Bibliography


Gilbert, T 2004, ‘Involving people with learning disabilities in research: issues and possibilities’, Health & Social Care In The Community, 12, 4, pp. 298-308, CINAHL with Full Text, EBSCOhost, viewed 26 April 2017


Macintyre, Ronald (2016). Approaching Participatory Design in “Citizen Science”. In: Design for Learning: 5th International Conference designing new learning ecologies, 18th -20th of May, Copenhagen


Nind, M. (2008) Conducting qualitative research with people with learning, communication and other disabilities: Methodological challenges, NCRM, Southampton


Appendix A

Human Research Ethics Committee (HREC)

From                     Dr Duncan Banks, Deputy Chair
                        The Open University Human Research Ethics Committee
Email                   duncan.banks@open.ac.uk
Extension                (6) 59198
To                       Jessica Carr, IET
Project title           How do people with learning disabilities understand citizen science?
HREC ref                 HREC/2017/2497/Carr/1
AMS ref                  n/a

Date application submitted: 17/04/17
Date of HREC response: 19/04/17

Memorandum

This memorandum is to confirm that the research protocol for the above-named research project,
as submitted to the OU HREC for ethics review, has been given a favourable opinion by the HREC
review panel.

Please note the following:

1. You are responsible for notifying the HREC immediately of any information received by you, or
   of which you become aware which would cast doubt on, or alter, any information contained in
   the original application, or a later amendment which would raise questions about the safety
   and/or continued conduct of the research.

2. It is essential that any proposed amendments to the research are sent to the HREC for review,
   so they can be recorded and a favourable opinion given prior to any changes being
   implemented (except only in cases of emergency when the welfare of the participant or
   researcher is or may be affected).

3. Please include your HREC reference number in any documents or correspondence, also any
   publicity seeking participants or advertising your research, so it is clear that it has been
   reviewed by HREC and adheres to OU ethics review processes.

4. You are authorised to present this memorandum to outside bodies such as NHS Research
   Ethics Committees in support of any application for future research clearance. Also, where
   there is an external ethics review, a copy of the application and outcome should be sent to the
   HREC.

5. OU research ethics review procedures are fully compliant with the majority of grant awarding
   bodies and where they exist, their frameworks for research ethics.

6. At the conclusion of your project, by the date you have stated in your application, you are
   required to provide the Committee with a final report to reflect how the project has progressed,
   and importantly whether any ethics issues arose and how they were dealt with. A copy of the
   final report template can be found on the research ethics website -
   http://www.open.ac.uk/research/ethics/human-research/human-research-ethics-full-review-
   process-and-proforma#final_report

Best regards,

Dr Duncan Banks, Deputy Chair
The Open University Human Research Ethics Committee

http://www.open.ac.uk/research/ethics/

www.open.ac.uk/research/ethics/

March 2015
## Appendix B

<table>
<thead>
<tr>
<th></th>
<th>Verbal - quotes</th>
<th>Actions</th>
<th>Timings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix D

Engagement:

1. How did the platform suit your personal requirements e.g was it easy to use?
2. How did you engage with each other during the project?
3. How enjoyable was it to work in a larger group or do work by yourself?

Community:

1. What did you think about the citizen science project?
   a. Enjoyment level
   b. Did it benefit you in any way? – further explain
   c. If you didn’t like it, what didn’t you enjoy?
   d. What was your favourite part and least favourite part?
2. Would this have been something you would have enjoyed doing at school?
3. Will you continue to use the platform to do projects by themselves?
   a. If so, what topics would you be interested in researching?
   b. If not, why not?
4. Did you feel that you were doing your own research?

What do people with learning disabilities understand by citizen science?

1. How would you explain citizen science to your parents/guardians or your friends? – example (research, fun, education) can’t use those three!
Appendix E

Focus group script – Final:

1. What are your views on the technology? E.g ease of use, anything you think should be changed
2. How did you work with each other during the project?
3. How enjoyable was working in a larger group – or would you prefer to do work by yourself?
4. What did you think of science before you did this project? (can be sentences or can be one word)
5. What do you think of science now you’ve done this project?
6. What did you think about the citizen science project?
   a. Enjoyment level
   b. Did it benefit you in any way?
   c. If you didn’t like it, what didn’t you enjoy?
   d. What was your favourite part and least favourite part?
7. Would this have been something you would have enjoyed doing at school?
8. Do you feel like researchers?
Appendix F
Appendix G

ANALYSIS:

To Analyse data you have
Collected

1. Road
2.

[Handwritten notes: Mission Impossible, Kim Possible, Kim Kardashian]

The Longest:

Lighthouse
Appendix H
Field note data analysis

1 – Community

Code 1 – Opinions and previous experiences with science/citizen inquiry:
- ‘One group member proclaimed ‘I am not a scientist’ and went on to discuss their negative experiences at school with science indicating it was mainly the writing aspect that put them off’
- ‘with 3 members immediately declaring they wished to join the study, one stating that they ‘love science’’
- ‘when asked what ‘citizen inquiry’ may be proclaimed ‘locked-in’ linking ‘citizen inquiry’ to prisons etc.’

2 – Support

Code 1 – Collaboration:
- ‘‘Team’ – term used often by many of the participants’
- ‘All choices were heard. Decisions were made as a group about the topic and everyone agreed on this topic putting in alterations as we went along’
- ‘Name of the group = ‘just do it – as a group’’
- ‘supported by others in the room, and the ideas came out of this – One participant straight after said we could research pubs and how loud they were – in reaction to participant 6’s comment. All were very supportive of the participant who didn’t like shouting by lowering their voices’
- ‘Upon leaving the building the group made the decision to change where they went to due to the heavy rain. A group decision was made that people would shout when they wanted to go in somewhere, and that we should turn left and work our way that way.’

Code 2 – Facilitation:
- ‘Facilitation was required, as technology was new. This became less as they used the technology more.’
- ‘One participant needed more support generally – with movement, talking etc’
- ‘Only facilitation needed was to structure the session and to make sure all voices were heard – in particular one participant who only speaks up when upset or when questioned’
- ‘prompting to explain and sometimes needed help to explain’
- ‘some participants needed to be kept on topic’
- ‘Once dinner had been eaten, one participant created the mission on NQuire with a large amount of support from me (technology wise and spelling wise). They were very proud of it and that other people could see it’

Code 3 – Peer support:
- ‘Supportive interactions – helping each other out with technology’
- ‘supported by others in the room, and the ideas came out of this – One participant straight after said we could research pubs and how loud they were – in reaction to participant 6’s comment. All were very supportive of the participant who didn’t like shouting by lowering their voices’
‘One participant helped others with spelling but then got annoyed and began to write for them. Bounced off one another when it came to picking words and linking one word to another. Lots of talking over one another’

‘Slightly off atmosphere in the group – some negative attitudes to one another’

‘One participant (P6) didn’t like the loud talking so covered their ears and asked every to stop. This prompted conversation about sound with one participant (P3) suggesting we look at pubs, followed up by another participant suggesting we look at how busy they were.’

‘All of the participants were supportive of this however, some did attempt to laugh and mock.’

Code 4 – Technology:

‘Facilitation was required, as technology was new. This became less as they used the technology more.’

‘Supportive interactions – helping each other out with technology’

‘Wasn’t working properly – google login wouldn’t connect to online NQuire-it platform’

‘The participants still needed some support with the recording function on the tech.’

‘All participants needed support with the technology, being shown how to record.’

‘Once dinner had been eaten, one participant created the mission on NQuire with a large amount of support from me (technology wise and spelling wise). They were very proud of it and that other people could see it’

3 – Engagement

Code 1 – Distraction:

‘1 person chose not to engage in the project due to their partner being present’

‘In the final place (a pub) two participants decided to get a drink. This then encouraged others and I bought drinks. Facilitated by me, this then became a small debrief, where all the participants appeared to disengage and play on their phones.’

‘One member was more concentrated on next task (playing football) – didn’t seem to engage in the project’

‘P1’s engagement in the project seemed to be massively affected by P5’s presence (not as engaged in the project, paying more attention to them).’

Code 2 – Engagement with the Technology:

‘Participants engaged with the ways in which different spaces were louder through looking at the tool – made preliminary findings. Does support engagement. One participant engaged with the technology and the way in which the sound bars moved.’

‘One participant was keen to write up the mission by himself – was very proud once he had done this’

‘P6 was disengaged instead choosing to look at the noise map on the tablets, making noises into them and seeing what that did.’

4 – Identity:

Code 1 – Decision Making:

‘Upon leaving the building the group made the decision to change where they went to due to the heavy rain. A group decision was made that people would shout when they wanted to go in somewhere, and that we should turn left and work our way that way.’

‘Decisions were made about how many places to go to (general consensus was 5), how long to spend in each place (5 minutes), and which places to go to’
Code 2 – Friendships:

- ‘Two were close friends – this affected the group dynamic – this could change as relationship fluctuates’
- ‘Slightly off atmosphere in the group – some negative attitudes to one another’
- ‘We then went on to discuss the project with the new participant being fairly dominating within these discussions. P1’s engagement in the project seemed to be massively affected by P5’s presence (not as engaged in the project, paying more attention to them).’

Code 3 – Independence:

- ‘Independence was shown in this session – choosing places to record. However, they were considerate of others choices.’
- ‘One clear leader emerged’
- ‘P1 & P5 ordered drinks for themselves and went to sit down’
- ‘In here four of the five participants went off on their own with P6 following them shortly after.’
Appendix I

1 – Community

Code 1: Previous experiences with science

A:

P5 – Like when you do umm when you do stuff like bar charts and tally charts and stuff like that
JC – OK and where do you do those
P5 – In Maths
JC – In Maths so is that at school or is that in a job
P4 & 5 – At college

B:

P1 – Right I’ve right in town in umm I was in town and uhh I was working just before starting my shift I was in town like literally early around 10. And uhh there was these umm there was these guys who were doing the umm what do you call it the virgin
JC – Oh is it the virtual reality thing you told me about?
P1 – Yeah can I tell all you guys?
JC – Yeah
P1 – So basically
P5 – Well we’re waiting
P1 – I watched it and he said click the first one he said look at the first one so I looked at the first one and said I’m looking at all these pigs how beautiful they look and how adorable they look as well like they’re so they’re so passion about life and stuff like it depends like how many cats they have like nine lives and we only have got one like one and pigs got like nine lives as well. Then I looked at this puddle and I was like, we were in a slaughterhouse and I’m like are you. I was looking and the next minute they were hanging the thing down.
P5 – He sounds like he’s gonna cry in a second
JC – It’s quite a distressing experience
P1 – Not only that I look I look at the chickens as well he said look at the second film I looked at the chickens I said look why. And that’s that’s how I become a vegetarian because at the end of the day I

C:

JC – Before you did this project if I were to say to you before this project if I were to say to you that you were gonna do science what would you have thought?
P5 – I’d have said count me in
P1 – Yeah please count me in
P5 – Seriously I have been literally ever since I started college I’ve been wanting to do science for like 4 years
P1 – There you go there’s your answer
JC – OK that’s very cool and what about everyone else
P5– I love science I love I love the prospects of science I would say
JC – OK what do you mean by the prospects of science?
P5 – Like how it how it like all fits together how like basically the way of the world
D:

JC – And what did you think of science at school and college? Did you enjoy it?
P5 – No
JC – No?
P2 – The one at school was boring
JC – OK
P2 – The one at college was fun!
JC – OK
P5 – Do you know what I actually didn’t like science at school cus all we were doing was writing and it was sort of boring

E:

P1 - How do you feel about that what I said to you
P3 – Upset
P1 – What I said to the whole group
P3 – Upset and guilty
P1 – I’m asking (P4)
JC – No it’s alright cus (P3) opinion so you said you were gutted didn’t you which is similar to yours (P1). Ok lets I think this is a conversation we can continue late cus I think it’s a big conversation to have
P1 – It is and me and me and (P5) agrees to it anyway

F:

JC – What were your ideas about science?
P3 – Fail one of them
JC – You failed one of them? OK so did you like science or did you not like science?
P3 – It was shit
JC – It was shit fair enough. What about (A) what did you think about science before you did the project
P4 – Good
JC – You liked science, what did you like about science?
P4 – You learn about, I dunno you learn about everything

Code 2 – Opinions on science:

A:

P3— Hard
JC – So what did you think did you think it was hard it was easy did you think it was fun
P3— Easy it was easy
P5— I think it was fun
JC – You think it was fun OK

B:

P5 – I wouldn’t consider that science I’d just consider it an experiment
Code 3 – Understanding of citizen inquiry:

A:

P5 – One word I that I also hope I would want to say legendary
JC – Legendary awesome (P4)
P4 – World-class
JC – World-class like it (P2)
P2 – Professional
JC – Pardon
P2 – Professional
P1 - Scientific

2 – Support

Code 1 – Peer support:

A:

P5 – He sounds like he’s gonna cry in a second

B:

P1 – I’ll tell you something, I love every moment of this project
JC – Ok and what did you enjoy the most?
P1 – Most likely introducing to you and all the people in the group

Code 2 – Collaboration:

A:

JC – And did you enjoy working with your friends or do you would you have preferred working with people that you didn’t know?
P4 – Didn’t know
P5 – Prefer to get to know people
JC – People?
P3 – Didn’t know
JC – You’d have preferred to work with people you didn’t know?
B:

JC – So do you reckon you enjoyed working in a big group or do you reckon you would have preferred to have done it on your own or in a smaller group

P3 – A smaller group

P1 – I would have done it I would have done it by partners but in a in a smaller group

JC – Why why so (P3) why would you have preffered to have done this in a smaller group. Or do you you not sure

P3 – Not sure

JC – What about you guys did you would you have preferred to have worked in a larger group or a smaller group

P4 – Oh yeah smaller group me and (P2) innit Desi boys

P2 – Yeah man

(giggling)

P2 – What boys?

P4 – Desi boys

C:

JC – So my next question gang how do you reckon you worked with each other during during this project

P3 – Easy

JC – Easy, you thought it was easy OK cool

P1 – Do you know I can’t I can’t complain cus at the end of the day it’s so wicked you know I would love to work with you again

JC – What about you guys what did you think

JC – Did you enjoy so how did you enjoy working together

P4 – Yeah

P2 – Yeah

P1 – Yeah now I enjoyed working with her as a couple yeah

3 – Engagement:

Code 1 - Enjoyment:

A:

JC – Ahh that’s nice so you liked working with the group what about you (P3) did you enjoy it did you hate it did you think it was OK

P3 – 50 50
B:
JC – (P4) did you enjoy it?
P4 – Yeah
JC – What did you enjoy about it?
JC – Did you enjoy it?
P4 – Yeah
JC – And what did you enjoy about it sorry I’ve asked you that three times now
P4 – Like going to the shop and the uhh restaurant and that

C:
JC – OK now this is a big question now that you’ve done the project do you feel like you’re actually researchers?
P1 – Yeah
P5 – You know what I came prepared for that question
JC – Did you?
P5 – I did
JC – OK
P4 – 100% yeah
JC – Yeah?
P2 – Yeah cus I got a phone
P5 – Can I tell you a secret though?
JC – Of course you can tell me
P5 – I feel like I’ve been a researcher my whole life

D:
P1 – I’ll tell you something, I love every moment of this project

Code 2 – Technology:
A:
JC – So we’ve got a little bit of a difference so we go from 78-83 so what do you think the differences might be if we were doing the road the difference in sound if we’re stood on the side of the road
P4 – How many cars passing by
JC – Cars passing by but why do you think yours and (P5)’s are different as to the loudest sound?
P5 – Umm cus we probably recorded it for less time
JC – OK so we did it for less time yeah
P5 – We did ours for like eleven seconds
B:

P5—There we go that’s what we got for the last one
JC—OK so wow let’s
P5—Compare
JC—So what can you see between the two of them
P5—They’re pretty much the same
JC—Yeah? Ok what’s similar between them
P5—How the lines
P4—Seconds
P5—How the lines go
JC—OK so is it going getting really loud is it getting quieter
P5—It’s really getting like a hat
JC—So it’s going up and down
P4—Yeah

C:

JC—So there’s actually a bit of a difference if you see on (P4)’s so what do we think that could be if P5 and (P1)’s is louder than on (P4)’s but we were in the same place what do we reckon could have made it a bit louder
P3—Traffic
JC—Traffic yeah that’s a good shout so we were in a restaurant so what else makes noise
P3—People
JC—People
P1—Music
JC—Music OK so do you remember there being music or do you remember people talking
P3—Talking and music
JC—Talking and music yeah so do you remember there being any music in the restaurant or do you remember if we were talking or if customers were talking
P5—I think I think a few of us were talking at one point
JC—OK so do you think that might have made a difference?
P4—Yeah
JC – You’re gonna watch OK cool so if we all go onto them and we select our bottom the last one right at the very bottom and press the plot button click on series I think I think you guys did your first one on here

E:

JC - what did you think to the app that you download that we used

P1 – You know what it’s absolutely fantastic

JC – You enjoyed it OK

P1 – You know what I’m gonna keep that app

JC – You’re gonna keep it

P1 - Cus I wanna use it

JC – OK that’s cool and what do you think you’ll do with it do more?

P1 – I’ll use it at Gap I’ll see how uhh the noise is levelled at Gap is and then I’ll let you know

Code 3 – Inquiry Process:

A:

JC – (P4) did you enjoy it?

P4– Yeah

JC – What did you enjoy about it?

JC – Did you enjoy it?

P4 – Yeah

JC – And what did you enjoy about it sorry I’ve asked you that three times now

P4 – Like going to the shop and the uhh restaurant and that

B:

P5 – I wouldn’t consider that science I’d just consider it an experiment

C:

P1 – We learnt how like how inform the loud

JC – OK and why do you think it’s important to know why places are louder any reason?

P1 – Because it could be a difference between louder

P5 – Depends what you consider loud really isn’t it

P1 – Yeah she’s got a point.
D:

P5 – I think the road
JC – You think the road was the loudest
P4 – Yeah

JC – So which one was the road number two so let’s have a look at number two how loud what did number two go up to oops sorry just click on that one so (P1) would you like to write for me that would be really handy if you could just write loudest

P5 – The road was up to was road the second one
JC – Yeah road was the second one so what did that go up to
P5 – We didn’t record it long enough
JC – I think (P4)’s went up to 83
P1 – The loudest
JC – OK so what we going for as our loudest
P5 – Probably the road
JC – OK and why do we think it’s the road?
(mumbling)
JC – so you think it’s the road from the bar that’s telling us how loud it was
P5 – I think we have to put the quietest as the lighthouse probably cus there was like hardly anyone in there
JC – OK so we’ll put the quietest as the lighthouse
P1 – So the quietest is going to be here or here

E:

P4 – Fun
P2 – FUN fantastic
JC – You think it was fantastic why did you think it was fantastic
P2 – Dunno
P1 – It’s just awesome

F:

P2 – Yeah this was the loudest
4 – Identity:

Code 1 – Independence:

A:

JC – So would you guys feel comfortable running the group
P3 – Yes (screaming) Oh my god!
P5 – How would we run it though
JC – You guys would be in my position
P5 – You’d have to let me run it since I’m the only girl in the group
JC – Would you feel comfortable doing that?
P3 – Yeah
P1 - Yeah
JC – If you got to run it with the rest of Monday Night Club lets say
P1 – Yep
P5 – Ohhhh
JC – Would you feel like you knew what you were doing
P4 – Yeah
P5 – Yeah
JC – With support from me obviously
P5 – Yeah

B:

P5 – I feel like I’ve been a researcher my whole life
JC – I like that that’s a cool little phrase
P5 – Seriously I do I literally every day when I get the chance I go to look for stuff and I research on it

Code 2 – Decision making:

A:

P5– It makes sense to it also makes sense to do it by hand cus doing it doing it on the tablets it’s not really something might happen with the I pads
JC – Yeah
P5– We might lose our data
JC – So
P5– So it makes sense to do it by hand
B:

P5 – I think the road
JC – You think the road was the loudest
P4 – Yeah
JC – So which one was the road number two so let’s have a look at number two how loud what did number two go up to oops sorry just click on that one so (P1) would you like to write for me that would be really handy if you could just write loudest
P5 – The road was up to was road the second one
JC – Yeah road was the second one so what did that go up to
P5 – We didn’t record it long enough
JC – I think (P4)’s went up to 83
P1 – The loudest
JC – OK so what we going for as our loudest
P5 – Probably the road
JC – OK and why do we think it’s the road?
(mumbling)
JC – so you think it’s the road from the bar that’s telling us how loud it was
P5 – I think we have to put the quietest as the lighthouse probably cus there was like hardly anyone in there
JC – OK so we’ll put the quietest as the lighthouse
P1 – So the quietest is going to be here or here

C:

P5 – There we go that’s what we got for the last one
JC – OK so wow let’s
P5 – Compare
JC – So what can you see between the two of them
P5 – They’re pretty much the same
JC – Yeah? Ok what’s similar between them
P5 – How the lines
P4 – Seconds
P5 – How the lines go
JC – OK so is it going getting really loud is it getting quieter
P5 – It’s really getting like a hat
JC – So it’s going up and down
P4 – Yeah
D:

JC – So there’s actually a bit of a difference if you see on (P4)’s so what do we think that could be if P5 and (P1)’s is louder than on (P4)’s but we were in the same place what do we reckon could have made it a bit louder

P3 - Traffic

JC - Traffic yeah that’s a good shout so we were in a restaurant so what else makes noise

P3 - People

JC – People

P1 – Music

JC – Music OK so do you remember there being music or do you remember people talking

P3– Talking and music

JC- Talking and music yeah so do you remember there being any music in the restaurant or do you remember if we were talking or if customers were talking

P5– I think I think a few of us were talking at one point

JC – OK so do you think that might have made a difference?

P4 – Yeah

E:

P5– Did you we could analyse our data by hand

JC – You reckon by hand OK

P5– I reckon it’s quicker and more efficient

F:

P5 – Just because I wanted to go in them I don’t have a reason

Code 3 – Scientific Literacy:

A:

P5 – I feel like I’ve been a researcher my whole life

JC – I like that that’s a cool little phrase

P5 – Seriously I do I literally every day when I get the chance I go to look for stuff and I research on it

B:

P5– I know what a hypothesis is

JC – Go tell us (P5)

P5– I watch big bang theory

JC – Ahh so we’ve got our own little scientist here

P5– So basically a hypothesis is something that you’re not sure of but you think you’ve got an idea of what it is
C:

P5 – They do it they do it on special computers don’t they
JC – So they do it on special computers
(group agrees)
JC – Ok so what they’re using what are they using on those computers
P5 – They’re using stuff like Excel and Powerpoint and stuff
JC – Cool and do you think they do it by hand or do they just do it by computers
P5 – I think they do it by hand sometimes it depends on what sort of scientist you are
JC – OK so what sort of scientists do you think do it on computers
P5 – Umm I’d probably say an archaeologist
JC – An archaeologist OK that’s quite cool
P5– They use computers to analyse dinosaur fossils
P1 – I love I love I love her I love her thinking

D:

P5 – Like when you do umm when you do stuff like bar charts and tally charts and stuff like that
JC – OK and where do you do those
P5 – In Maths
JC – In Maths so is that at school or is that in a job
P4 & 5 – At college
JC – At college
P4 – Yeah
JC – OK so you think you were doing analysis at college
P1 – Yeah maybe

E:

JC – So what sort of analysis do you think they do in football?
P4 – Like goals and like penalties and
(mumbled speech from other participants in the background)
JC – OK so you think they’re analysing what are they analysing
P4 –Analysing basically goals and um
P5 – Do it in a minute
P4 – So basically half time and full time
JC – Oh wow ok
P4 – So what they do they decide like goals and uh like uh like penalties and fouls and uh offsides