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Listen Up: Using young people's views to help shape education to support psychosis literacy

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Listen Up: Using young people's views to help shape education to support psychosis literacy

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Abstract

In the UK, schools are gradually embracing their responsibility to cater for young people's mental wellbeing. Exploring young people's Mental Health Literacy (MHL) is an area however that is still in its infancy. Specific focus has explored young people's literacy of the condition of psychosis, considering how useful it is to provide biomedical information as a MHL intervention within schools. Such an approach reduces a more holistic understanding of mental illness and portrays young people as illiterate. My goal is instead to value young people as competent social agents with existing social and personal meaning in their understanding of mental illness.

A peer research methodological approach has given young people the chance to explore their views and opinions without adult influence. Thirteen PRs (Peer Researchers) were involved in focus group sessions from two Further Education Colleges in the North East of England: 1) To explore young people's own understandings of psychosis 2) To explore what aims young people may feel psychosis literacy should address and 3) To explore what strategies young people believe would be the most useful to cater for young people's educational and health needs.

AR-led (Adult Researcher) and PR-led data has been assessed for the influence of demand characteristics, adding new understanding of how young people socially constructed their responses according to an adult or non-adult audience. The need to understand young people's social, cultural, and personal meanings attached to psychosis have been an important first step to help appreciate what holistic methods and content of literacy would be most meaningful and right for young people.

Nevertheless, an emphasis on academic attainment in schools and the influence of key stakeholders' views and opinions (including teachers and parents) may challenge the viability of implementing any form of psychosis literacy within the school environment. It is likely that adult concerns would remain and form a barrier towards listening to the voice of young people's views and opinions in favour of their own agenda.

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Preface

Before I begin my thesis, I feel that it is important to supply the reader a background behind how this research started. Taking a reflexive approach will hopefully help the reader understand the rationale for the decisions made throughout the study. Without this explanation, the reader would not be able to make a judgement on the final outcomes of the study (Willig, 2001). This preface will therefore try to explain what factors led me to first consider young people's mental health literacy and the process of challenging my own epistemological, methodological, and political positioning when deciding the course of action to take in this research (Smyth & Shacklock, 1998).

The use of reflexivity, however, should cautiously be used. It is not my intention to use this preface as a form of confessional act or a cure to escape from the consequences of our position as a qualitative researcher (Patai, 1994). Instead, the intention of engaging in personal and professional reflection is to expose to the reader the complex decisions I have had to make during this journey to obtain the outcome of this research study (Pillow, 2003). The context of the researcher's position is an important starting point to illustrate credibility in my research findings (Pope & Mays, 1999).

i The Primary Researcher's professional background

It would be very naïve to consider any researcher being entirely objective or impartial, and primarily their motives need to be scrutinised to fully understand the nature of the research study (Moore, Noble-Carr & McArthur, 2016). I will therefore start by acknowledging and explaining why my 'dual' professional background as a qualified secondary school teacher and mental health nurse has led me to choose to investigate young people's understanding about psychosis and their views about developing psychosis literacy.

During my early school life, it was always my ambition to become a secondary school History teacher. I was always interested in History and wanted to inspire young people about this subject. The reality of my experience as a secondary school History teacher opened my eyes to the complexity and challenging nature of the pastoral role of the teacher, facing disengagement and disruptive behaviour among young people. I personally struggled during my teacher training when faced with these pressures and felt unprepared and unskilled to deliver effective pastoral support. Unfortunately, at times I felt left in the dark about young people's social and emotional background to be able to support them at a personal level. Feedback from my teaching observations was that I needed to have more classroom management skills. It was my inexperienced teaching style that did not effectively control the bad behaviour of these young people. The reasons why young people behaved in such a disengaging manner had not been considered.

The experience of my teacher training was a very frustrating and demoralising one. Even though I loved teaching, and I successfully completed my teacher training, I made the decision that I could not continue in this profession. I did not agree that behaviour problems of young people's behaviour was entirely dependent on better classroom management but felt ill-equipped to deal with the pastoral role needed for these young people. The young person's voice became drowned out within the authoritarian expectations of how a teacher should act. I felt that more understanding and time is needed to understand these young people.

It was this struggle that directed my attention and interest in how the school environment could support teachers and pupils in terms of appreciating the importance of the mental health needs of young people. I felt that it was unrealistic for secondary school teachers to have to deal with these various pastoral roles as well as their teaching role. More support is needed to ensure that mental health was dealt more appropriately in schools, rather than avoided or not perceived as an educational aim.

I therefore made the decision to change career. From the advice of my parents, both from nursing backgrounds, I discussed the possibility of entering the mental health nursing profession. Working within the mental health setting was an arena where I would have more opportunity to work on an individual basis to explore the mental health needs of individuals. This was an area which I was unable to achieve as a secondary school teacher.

Mental health nursing had clear links to the pastoral skills I had become interested in developing as a secondary school teacher. I finally was able to dedicate more time and focus on the individual's mental health and increase my understanding behind reasons why someone may be behaving in a certain manner. For example, during my experience in child adolescent mental health services my feelings of resentment against young people's disruptive behaviour in schools changed as I became more aware of what was happening behind the scenes in these young people's lives. This gave me an alternative perspective of considering young people's needs within an educational setting and motivated my research intentions to build a bridge between mental health and educational services.

My research interests also became specifically attached to psychosis, as I worked as a community mental health nurse within a psychosis community mental health team. I particularly enjoyed my opportunity working with young people with psychosis in liaison with the early interventions in psychosis team (EIP) and children and adolescents mental health services (CAMHS). Stigma, discrimination, and lack of understanding about psychosis were prominent issues that caused barriers for early help-seeking among young people with psychosis. Psychotic experiences were too distant for other people to relate to, adding further stigma towards this disorder compared with other mental illnesses.

From these experiences, it was clear to me that there was a great need to address young people's MHL needs within the school environment. I wanted to support health promotional campaigns such as YoungMind's 'Wise Up' to re-balance the lack of focus on young people's mental health and wellbeing within the school environment (YoungMinds, 2017). The role I envisaged of the mental health nurse within the school setting was a development I was particularly interested in which led to the development of my initial research questions which shall now be outlined.

ii Initial ideas

Good research questions have been praised as the creation of the researcher's own values, passions, and preoccupations (Russell & Kelly, 2002). This certainly stimulated the start of my PhD journey in wanting to improve the mental health literacy of young people. Without these values, it would be unlikely that momentum and motivation in my research would have been maintained or even conceived, as my aims overlapped two distinctly different academic fields in education and mental health. Equally, criticism could be directed at the researcher for directly attempting to interpret or direct the study towards satisfying the researcher's own objectives. Hence it is important for researchers to demonstrate their awareness of personal reasons why the research study has taken place and understand how best to deal with them (Pillow, 2003).

The initial ideas of my research focused specifically at looking after the mental health wellbeing of young people within the secondary school environment, not only applicable to CAMHS. The problem I foresaw was that young people did not view mental health as an area that was relevant to them. The amount of stigma that surrounds mental illness from my experience in CAMHS prevents many young people from accessing help. Simultaneously, from my experience as a secondary school teacher I was aware that the lack of pastoral support in school environments may be due to teachers not feeling comfortable or prepared enough to discuss mental illnesses with young people. I therefore wanted my study to start the process of creating an intervention to support young people's mental health needs during their experiences at secondary school. In my professional opinion, the intervention needed should aim to increase young people's awareness about mental health and reduce the amount of stigma that surrounds mental health topics. Reflecting on my views, beliefs and experiences surrounding this issue is vital in considering how these might affect this study through the political and social identities I hold (Pillow, 2003).

My original aim focused on supplying the correct knowledge and understanding about mental health wellbeing and illness to young people for the sole purpose of reducing stigma and improve young people's health promotion behaviour in encouraging young people to seek help and support. Within this perspective, any discourse that varied or challenged professional opinion or guidance was potentially stigmatising or incorrect. I initially accepted this agenda without any questioning.

When conducting my research, I was also aware that my thoughts and ideas were working against a current political climate that was withdrawing support for a school curriculum that held responsibility over young people’s wellbeing. For example, support had just been withdrawn from the Social Emotional Aspects of Learning (SEAL) programme, and PSHE was still not favoured as a compulsory subject within the National Curriculum. Hence, I was particularly concerned about the direction of the Government’s agenda on young people’s wellbeing within the school environment. To challenge this political tide, a bottom-up action research approach was considered the most appropriate research method to value a wide spectrum of views from young people, secondary school teachers, and parents. From these first ideas, I had to decide then realistically what could be achieved in this PhD thesis. The next section shall illustrate how these choices were made.

iii Time to be realistic!

As Glesne & Peshkin (1992) point out, the potential demands of qualitative research can lead to near total absorption and lack of realism in what is achievable. It was a crucial step for me to accept and acknowledge the limitations of what I could achieve in my research, and the extent I could honestly and openly address these issues (Ruby, 1980). The demands placed on this research project were not realistically achievable, and the nature of the research aims conflicted with my qualitative approach.

My preoccupation in finding out how to assess the effectiveness of a literacy intervention was one area that was first challenged in my research. The term effective placed a demand to assess improvements in young people’s literacy. What this did not appreciate was the need to explore existing knowledge or understanding, or an appreciation of the appropriateness and suitability of pedagogical approaches used in literacy interventions. Assessing effectiveness did not create the opportunity to allow qualitative data to develop regarding what literacy approach is needed or wanted. It would surely be inappropriate for the researcher to decide specifically what approaches to assess as effective in the first place, without obtaining young people’s views about their educational/health needs first.

The ambition to explore a wide audience of young people, teachers and parents proved an obstacle. I viewed all these individuals' opinions as valuable to implement an acceptable intervention within secondary schools. As a parent and teacher, I felt responsible to protect young people and believed that if a collective agreement could be achieved, there would be more chance for an intervention to be viable. This concern questioned my judgement and motive in having to consider different parties' concerns, as surely this only reinforced the idea that adults are the main decision-makers rather than the young people.

Moreover, throughout my own mental health nursing experience I was aware that multiple social meanings are attached to the experience of hearing voices, and that these meanings are often reduced within a biomedical construction. For example, my exposure to the Hearing Voices Network raised my awareness of how meaning attached to the experience of psychosis is far from straightforward. The type of literacy intervention I initially considered could potentially prevent value being attached to young people's alternative meanings or experiences.

It soon, therefore, became clear to me that my initial ideas were built upon my own motives to develop a literacy intervention needed for young people and had significantly neglected consideration of young people's views or meanings they held regarding the experience of psychosis. This self-reflection changed the direction of my research towards a more pressing need to challenge the motives involved in trying to implement an intervention that assumed young people were necessarily illiterate and vulnerable (Moore, Noble-Carr & McArthur, 2016). The importance of being reflective illustrates how researchers can take a step back and question assumptions based on political, professional, and personal views.

The consequence of this process of self-reflection has been the journey of engaging with young people which helped to form and develop my research questions, whilst also giving the opportunity to problematize the research design of this study.

iv End of the journey?

One then questions whether there is an end in sight of my PhD journey. Have I been reflexive enough to understand the phenomenon explored, and achieved a correct portrayal of the meaning produced by young people? Hopefully my level of self-examination while working with the young people and utilising PRs will allow biases and assumptions to be explored and understood. However, I accept that human interaction is complex and multileveled to the extent that this journey can never, and should never, stop. It is the researcher's duty to remain reflexive to develop our awareness and critical approach to challenge our own epistemological and ontological perspectives.

Birch (1998, p183) described her research experiences as the process involved in the creation of 'the self' as a researcher:

> 'The more I progressed into the analysis and the writing up, and so into my own personal, private space, the more I became aware of the emergence of my own sociological identity. I was the author who was choosing to make certain arguments and explanations. Hence it is the recognition of the mirror image that was my own inner journey of self-discovery. The more I told my sociological story the more my sense of self as a sociologist was discovered.'

The journey that I began to take in my PhD has increased my awareness of my own personal assumptions and feelings. The process of challenging these beliefs has increased my level of self-confidence to justify my arguments and explanations and has acknowledged what this research has been unable to accomplish, or potential weaknesses involved in the study. It has been a journey that has enabled me to discover more about myself as a researcher as I reflected on the need to validate my own actions, values and perceptions on how choices were 'crafted' throughout my research study (Cutcliffe and McKenna, 2002; Pillow, 2003; Kingdon, 2005; Gerrish and Lacey, 2006). There is therefore no end in sight in my journey, and the process of reflexivity intends to ensure that there is no end.

Acknowledgements

Firstly, I would like to express my sincere gratitude to my supervisors Dr Michelle Glascott and Dr Michael Hill for the invaluable support, advice and guidance that they have provided me at the last stages of my PhD journey. Without their support, there is no doubt that my studies would not have been completed. They have shone a needed light to direct me in the right direction, and I must thank them for their level of patience, motivation, and immense knowledge they have given to me during times when I needed most help and support.

Besides my supervisors at Northumbria University, I would also like to thank my previous supervisors, Professor Janet Shucksmith, Dr Mandy Cheetham and Dr Lisa Arai, who all guided and motivated me with their insightful comments and encouragement that shaped my thesis. It was with this level of inspiration that motivated me to question my own views, thoughts and opinions and widened my research from various perspectives. My sincere thanks also go out to my colleagues at Northumbria University, who have all been very understanding, and have listened to my thoughts and arguments with a critical ear.

A huge amount of credit must also be given to all the young people involved in this research project. Unfortunately, the PRs were unable to co-author this project, but it is without saying that without their level of interest and commitment to be involved in this project there would have been no possibility of obtaining the data that has shaped this thesis. I hope I do you all justice in reflecting your views.

Last, but not least, I would like to thank my family: my parents, Kathleen and Gooroodutt, my brother, Mark, my wife, Krista, and my children, Matthew, and Melanie for all the support they have given me. I would not have been directed into this path if it was not for my parent’s support and guidance, thank you for the sacrifices you have made for me. My brother has spent time reading my work and has always been there offering suggestions. My wife has always supported my studies and has constantly pushed me through this journey, especially when my morale was down. Thanks for putting up with me! Finally, Matthew and Melanie – thank you for being my main inspiration – I did this for you! I hope you are proud of me and forgive me for the times I have not always been there for you.

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas, and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by Teesside University's School of Health & Social Care Research Governance and Ethics Committee on the 5th October 2012 (see Appendix 7).

Name: Andrew Ramtohul

Signature:

Date: 31/01/19

List of Operational Definitions

At Risk Mental Health State (ARMS)	Term used by health professionals to describe young people experiencing perceptual changes that may be early, low-level, signs of psychosis. It is unusual for psychosis to just happen. Identifying young at risk could help delay the onset of psychosis, or even stop the experience of a first episode of psychosis altogether.
Emotional Literacy	The ability to understand your own and others' emotions by listening and empathizing with others' emotions. Aim to improve relationship building and challenge power differentials within society.
Emotional/Mental Wellbeing	The ability for an individual to function in society and meet the demands of everyday life. The basis for healthy behaviour, educational attainment, prevent behavioural problems and mental health problems.
Mental Disorder/Illness	Clinically significant disturbance in emotional regulation, cognition or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning.
Mental Health	Umbrella terms to describe both concepts of emotional/mental wellbeing and mental disorder/illness. It is a state of wellbeing

	in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to contribute to her or his community.
Mental Health First Aid (MHFA)	An educational course which teaches people how to identify, understand and help a person who may be developing a mental health issue. In the same way as we learn physical first aid, Mental Health First Aid teaches you how to recognise those crucial warning signs of mental ill health.
Mental Health Literacy (MHL)	The knowledge and beliefs about mental disorders held by an individual which might aid the recognition, management, or prevention of mental disorder
Peers	Person equal in rank or merit, sharing similar experiences and status; belonging to the same societal group especially based on age, grade, or status.
Peer Research Methodology	Participatory research methods that involve members of the research target group adopting the role of active researchers.
Psychosis	A mental health problem that causes people to perceive or interpret things differently from those around them. This might involve hallucinations or delusions.

Social Emotional Aspects of Learning (SEAL)	A comprehensive, whole-school approach to promoting the social and emotional skills that underpin effective learning, positive behaviour, regular attendance, staff effectiveness and the emotional health and well-being of all who learn and work in schools.
Stereotyping	Thoughts or beliefs about the attributes of individuals or certain ways of doing things, which may or may not accurately reflect reality. Occurs without conscious awareness.
Stigma	Stigma is an umbrella term that collectively refers to stereotypes, prejudice, and discriminatory behaviour against people with mental illness (Hinshaw & Stier, 2008).
Young People	Older or more experienced children who are more likely to be able to make decisions for themselves; in a period of transition from the dependence of childhood to adulthood's independence. Participants and PRs were aged 16-17 years old.

Chapter 1: Introduction

1.1 Key concepts considered

This research investigation draws upon divergent concepts interlinked within a complex multi-disciplinary question – how are young people's level of knowledge and understanding of psychosis assessed and what are the psychosis literacy needs of young people? These concepts appear divergent and exist separately within the fields of mental health promotion, psychiatry, pedagogy, and childhood studies. However, they are all fundamentally linked when considering young people's psychosis literacy needs. Figure 1 identifies the four main concepts considered in answering my key investigation question.

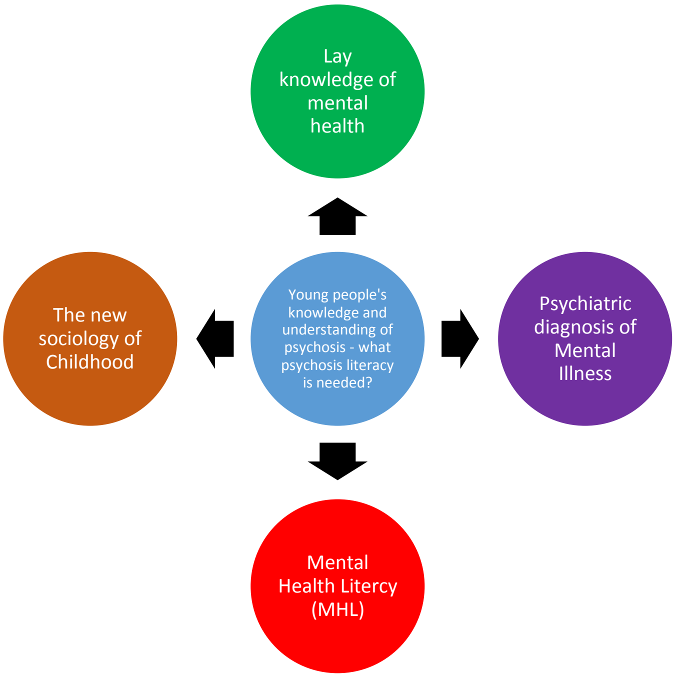


Figure 1: Key concepts

These key concepts will be explored, questioned, and challenged within a separate chapter entitled 'Theoretical Background'. Nevertheless, this introduction will start to explain the complex challenges involved in considering these concepts to illustrate how they have shaped and directed how this research has considered young people's psychosis literacy needs.

The first step taken will be to provide a background explanation of the problems, with the aim of improving young people's mental health literacy. The dominance of a biomedical psychiatric diagnosis framework to reduce levels of stigma is not entirely considerate or holistic enough when evaluating young people's level of literacy. An explicit explanation will follow why psychosis, and not general mental health, literacy was specifically chosen. The relevance of the topic of psychosis for young people's health and education needs will be explained.

The concepts of valuing lay knowledge of mental health and the new sociology of childhood have provided a theoretical framework to challenge the MHL approach and problems related to psychiatric diagnosis. This supplies specific explanation why this research turned its attention to listening to young people's views and utilised a peer research methodological approach.

Finally, this introduction will end with an acknowledgement of the limitations of my findings contextualised within the real world setting of young people's education. This will help the reader to appropriately situate the implication of my research findings, and what the next steps should be in this field of research.

1.2 Challenging the concept of 'Literacy'

The concept of 'literacy' in this thesis has been intentionally used to challenge the connotations associated with the level of young people's illiteracy. When using the term 'illiteracy' in this thesis, there is no intention made to agree with the connotations associated with this term, instead the use of the term is purposefully conducted within a critical stance. An explanation why such a term is value-laden will now follow.

Making judgements against someone's level of knowledge and understanding creates a danger that one may impose incorrect interpretations of what others perceive as being illiterate. For example, Gattuso, Fullagar and Young (2005) illustrated the problem of viewing women who have experienced depression as illiterate if they refused to take up the expert view of depression. Instead, it was important to place more value and understanding of women's belief structures in formulating their understanding of depression. Similarly, in this thesis, the stance taken is that young people should be understood and appreciated as competent social actors, making sense of their own belief structure of psychosis (Christensen & James, 2000; James & James, 2004). It is inappropriate to assume that young people are illiterate. All young people have their own level of literacy that should be respected and not perceived as irrelevant or ‘wrong’ from an adult perspective. Young people’s experiences and beliefs of their own health and behaviour should be appreciated as they often run counter to an adult-led agenda (Wills et al., 2008).

It is important not to determine how literate a young person is based on their ability to give biogenetic explanations or willingness to apply a diagnosis (Read et al., 2006). This criterion has led to literacy approaches simply dumping biomedical information on young people as an oversimplified solution to reduce stigma and improve help-seeking behaviour. In fact, there is evidence that the provision of biomedical information has increased levels of stigma towards those with psychosis (Penn et al., 1994). A systematic review conducted by Mellor (2014) held no compelling evidence to support existing school-based interventions in reducing mental health stigma. Hence, the content of literacy supplied is a principal factor that needs further consideration if we wish to increase our chances of reducing levels of stigma (Penn et al., 1999; Luty et al., 2007; Penn et al., 2003). It is not a simple solution, as originally suggested by Jorm (1997), that one can provide literacy as a solution to end the level of stigma and discrimination that is still directed at individuals.

Moreover, within the definition of MHL, there has remained a narrow focus towards the aim of ‘aiding the recognition, management or prevention of mental disorder’ (Jorm, 2012, p231). No consideration is given towards the emotional/mental wellbeing dimension within the concept of ‘mental health’. The term ‘mental health’ proves to be problematic in the interpretation if its meaning attributed by the young people. Hence, the decision that a more specific focus should avoid such confusion and ambiguity generated by the terms ‘mental health’ or ‘mental disorder’ or ‘mental illness’. All of which are misleading in meaning and too wide in spectrum to enable a clear discussion to occur when considering young people’s literacy needs.

1.3 Why specifically ‘Psychosis’ Literacy?

My justification for focusing on psychosis literacy rather than mental health literacy for young people is multi-factored. It was not solely based on my own personal interests, as mentioned in the Preface. In fact, it was not my intention to focus specifically on psychosis but to consider the wide spectrum of MHL needs.

For this study, a wider discussion and awareness around the nature of psychosis was felt to be more appropriate, encompassing a range of symptoms such as ‘hallucinations, delusions, and/or gross disorganisation of thought or behaviour’ (Tsuang et al. 2000, p1041). ‘Psychosis’ is an umbrella term to describe symptoms that can occur when experiencing schizophrenia, bipolar disorder, schizoaffective disorder, dementia, some personality disorders, Parkinson’s disease, drug/alcohol abuse, severe stress or anxiety, severe depression, or sleep deprivation. Hence, using the term ‘psychosis’ should reduce the limitations associated with the term ‘schizophrenia’. Although it is acknowledged that I am still using the diagnostic label of psychosis and it is also anticipated that young people will be more familiar with the term schizophrenia, and when discussing psychosis may synonymously refer to schizophrenia.

There are different literacy requirements for the wide spectrum of mental disorders, as significant differences exist in public attitudes towards different mental disorders (Crisp et al., 2000). Psychosis remains one of the most stigmatised mental disorders associated with negative media coverage and public imagery of violence, dangerousness and unpredictability (Wahl, 1992; Taylor & Gunn, 1999; Jorm & Griffiths, 2008; Angermeyer & Dietrich, 2006; Wright et al., 2011). More negative attitudes have been associated with schizophrenia than with depression or post-traumatic stress disorder (PTSD) (Arnanas, 2008; Angermeyer et al., 2004). There is a greater need to find an educational intervention that can address specific literacy needs surrounding the imagery of someone experiencing a psychotic episode. It is hoped that this focus will provide more clarity on understanding how young people view and understand psychosis, including what they view their literacy needs are, rather than mental health in totality.

When reviewing current research literature about school-based MHL interventions, it soon becomes apparent that psychosis or schizophrenia are not conditions that are focused upon. Howard et al. (2008) argued that school-based interventions would only be effective to reduce mental health stigmatisation if less focus was placed on schizophrenia, and more focus on interventions that could highlight mental health conditions that students are more likely to encounter amongst peers, for example anxiety disorders. Naylor et al. (2009) therefore decided to consider six lessons on mental health issues common to young people: stress, depression, suicide/self-harm, eating disorders, being bullied and intellectual disability. It was considered that these mental health topics were more relevant to the young person.

This research disagrees with this rationale. Instead, the argument put forward is that avoidance in discussions surrounding psychosis could increase the extent of stigma and fear associated with psychosis. Young people have been identified as a group unlikely to seek help for their own mental health needs, and do not know how to approach or talk about mental health (Potts, Gillies & Wood, 2001). The perception that psychosis is too serious a condition to be relevant for young people is expected to create the feeling of othering. Whereas, the opportunity to enter an open discussion about psychosis could enable this taboo to be broken (Bulpitt & Martin, 2010). The relevance of psychosis for young people instead shall next be considered.

1.3.1 What relevance does Psychosis have for young people?

In the 2004 UK survey, it was estimated that one in ten children under the age of fifteen has a mental health disorder (Green et al., 2005). It has also been surveyed from a total of 87 projects involving 6,178 young carers in the UK that 2,472 of these young carers looked after family members with a mental health problem (Dearden & Becker, 2004). National estimates for England, Wales and Scotland have been between 6,000 and 17,000 children and young people are carers for their parents with mental health problems (Aldridge & Becker, 2003). The real number is likely to be significantly higher due to the invisible nature of mental health (Cawson et al., 2000).

In terms of psychosis, the National Institute of Clinical Excellence (NICE) calculated in 2002 that 4 in every 1000 children aged between 5 and 18 suffered from psychotic disorders (NICE, 2013, p35). Schizophrenia accounts for 24.5% of all psychiatric admissions in young people aged 10–18 years and the admission rate is 0.46 per 1000 for this age range (NICE, 2013). There is a rise across adolescent years when the incidence increases most from age 15 onwards (NICE, 2013). The prevalence of psychosis rapidly increasing between the ages of 15 to 17 supports the importance of addressing and minimising the risks related to young people's wellbeing during this age group (Kessler, 2007). Particular relevance is associated with young people's use of drug/alcohol abuse, experience of severe stress or anxiety, severe depression or sleep deprivation as risk factors for the early intervention services to identify young people at risk of mental health status (ARMS) in order to delay the onset of psychosis, or even stop the experience of a first episode of psychosis altogether (Yung et al., 1996). Psychosis literacy could therefore contribute efforts to raise awareness of young people's own symptoms of psychosis.

One could argue that overall the statistics are too small (in comparison with other common mental health issues) to make psychosis relevant for young people's wellbeing. Therefore, why should there be a focus on psychosis for young people? In response, caution needs to be applied to this statistic alone as it is based on identified psychotic disorders, excluding undiagnosed, misdiagnosed, other psychotic illnesses or out-of-the-ordinary experiences (Heriot-Maitland et al., 2012). The true incidence of psychotic experiences in young people may therefore be a great deal higher. The undisclosed iceberg of young people with mental health problems, such as psychosis, may be exacerbated by young people not wanting to seek help or know how to approach or talk about this topic (Potts, Gillies & Wood, 2001).

Hence to base an argument that psychosis is not relevant to young people based only on the premise that it is a rare condition for young people seems to be too naïve. Assumptions of lack of relevance have been mostly adult-orientated, without asking how important or relevant is psychosis from a young person's perspective. Do young people view psychosis as part of their own wellbeing, as a separate anti-stigma school-based programme directed at other people, or both, or neither? One cannot deny that young people are exposed to mental illness issues personally, as well as through day-to-day exposure. Surprisingly, however, young people are rarely given the opportunity to explore or discuss what serious mental illness means to them.

The relevance of psychosis literacy could aim to reduce the level of stigma and discrimination held by young people, helping to ensure that other young people and the public do not feel stigmatised. Young people have been perceived as holding the strongest discriminatory views (DH, 2007), learning from an early age that mental health is associated with ‘personal failure’ and that it is acceptable to socially exclude peers with mental health problems (Kirkcaldy, Eysenck & Siefen, 2004; Hayward & Bright, 1997). It is not surprising then that the WHO (2005) has calculated that 80% of adolescents are deterred from seeking help with psychiatric disorders due to stigma. Improved literacy could be used to improve diagnosis, decrease stigmatization, and facilitate early help-seeking behaviour (Secker, Armstrong & Hill, 1999; Kelly, Jorm & Wright, 2007; Sakellari, Leino-Kilpi & Kalokerinou-Anagnostopoulou, 2011). The next question to consider is why has there been limited development of addressing the topic of psychosis within the UK school environment?

1.3.2 Why has little progress occurred for the development of psychosis literacy?

Despite strategic calls for action as long ago as 2002 by the Newcastle (UK) Early Psychosis Declaration that ‘all 15-year-olds are equipped by mainstream education to understand and deal with psychosis’ (Bertolote & McGorry, 2005, p116), the development of school-based MHL interventions still remains in its infancy in the UK. Little research has focused any consideration on asking young people why psychosis literacy would be important for them within the areas of early intervention, public health, and health education. We will now explore the reasons why this has been.

One of the possible reasons is because the concept of psychosis literacy exists ‘between the worlds of mental illness intervention (psychiatry), mental health problem prevention (public health) and mental health promotion (health promotion and health education)' (Nind & Weare, 2009, p2). Little joined-up thinking between these worlds has meant a neglect of coherent research and a lack of coherent aim towards the need for psychosis literacy. It is in the intention during this research to ensure joined-up thinking does occur in the aim of achieving a form of psychosis literacy that addresses young people's holistic needs.

The school curriculum has promoted the general emotional wellbeing of young people; for example, the UK National Healthy Schools Programme advocated increasing emotional health and wellbeing (EHWB) support for students (Department of Health, 2004). It has not been the place for schools to be involved in the medicalisation of young people; teachers would not view themselves as prepared or have responsibility for young people's mental health. In educational terms, there is justification to be concerned with the emotional wellbeing of young people to improve educational attainment and improve the emotional literacy of young people. Education, however, has not been in the arena of dealing with the young person's mental health needs. Discussion with young people in UK schools about mental illnesses has generally been avoided as not relevant for young people, especially psychosis.

In terms of school's concerns about developing emotional literacy and emotional wellbeing of young people, there are still concerns that the role of the school has become too therapeutic and has neglected its educational role (Ecclestone & Hayes, 2009a; 2009b; Ecclestone, 2007). Ecclestone & Hayes (2009a; 2009b) put forward the argument that young people have been viewed as 'diminished selves' and increasingly 'narcissistic' as the educational world has surrendered to therapy professionals.

It has only been a recent development that PSHE has become statutory within the National Curriculum through the Children and Social Work Act (2017) in secondary schools. The Targeted Mental Health Services in Schools Project (TaMHS) was also only supported for a period of 3 years before it ceased to exist. Significant conflict with the 'target-driven culture' of secondary schools, has seen such initiatives as 'obstructing academic work', and have therefore become tokenistic and devalued (Formby & Wolstenholme, 2012). These points illustrate the difficult battle that has existed in the role of schools in supporting the young person's mental health.

The struggle that has existed in developing a school-based MHL programme was my starting point in building a bridge between the different academic fields identified by Nind & Weare (2009). As both an educationalist and health professional, I felt well placed in addressing this problem. The starting point was to rectify the problem of not giving enough value and prominence in considering young people's views.

1.4 The importance of young people's views

As stated in my preface, it soon became apparent that my initial ideas of trying to obtain all stakeholder's opinions and views regarding the nature of MHL interventions did not scratch enough of the surface appearances of the problem in question (Harvey, 1990). When reflecting on my preconceived ideas that there was a need for young people to have MHL, it became clear that there existed unquestioned assumptions that young people's MHL was poor and resulted in attitudes rooted in stigma.

This led to a research approach that was much more careful and cautious to prevent the risk of the researcher becoming trapped within an institutionalised reductive perspective about young people's MHL. The dominance of cultural meanings that exist within the mental health and educational professional arenas could easily fail to understand young people's needs. Accordingly, educational researchers need to accept public pedagogy without applying a reductionist or superiority perspective of educational practice (Burdick & Sandlin, 2010).

An example of understanding the importance of hearing the young person's voice about their MHL needs occurred in 2015 when 967,000 young people (aged 11-18) voted in the UK Youth Parliament Make Your Mark campaign. Out of 10 topics, 5 were prioritised in the vote, which included the need for 'a curriculum that prepares us for life' and to 'improve Mental Health Services for young people' with specific advice that 'mental health education should be compulsory and challenge stereotypes' (Reed, 2012: ukyouthparliament.org.uk). They also prioritised MHL for young people in their national campaign for 2016 and recommended that ‘mental health education should form a core part of the PSHE curriculum, to promote wellbeing and resilience in children and young people and prevent mental health problems developing’ (APPG, 2015, p23).

Despite these priorities, no real direction has considered what young people feel would be the most appropriate method and content needed to implement this type of curriculum change. There is a need to challenge the politics of childhood, and actively listen to what young people’s health educational needs are (Schäfer & Yarwood, 2008). The decision was made that a more critical discussion was required to cut through the historical and social contexts of young people’s mental health literacy. The objective social appearance of young people’s illiteracy and stigma was far from simple, and illustrated the need for my study to deconstruct and reconstruct the notion of young people’s mental health literacy, and not take it for granted.

My attendance at the Involving Children and Young People in Research and Consultation on Thursday 22nd March and Friday 23rd March 2012 at the Centre for Research on Families and Relationships in the University of Edinburgh helped me explore how an adult professional perspective may be interpreting young people’s mental health literacy needs inappropriately.

This made me question my initial professional ideas that young people were illiterate about mental health. By considering a young person’s social constructional understanding of mental health, young people’s level of stigma and lack of knowledge and understanding about mental health could be questioned. It was this questioning that altered my professional concerns about the ‘vulnerability’ of young people and made me rethink how an adult-dominated education and mental health perspective has interpreted young people’s literacy.

My identity as a researcher was an important influence on how young people responded to me through the focus group sessions (Coffey, 1999). My research methods changed in response, acknowledging that there was a need to avoid an adult professional perspective. The use of young people as researchers was considered in case-study examples in Edinburgh as a method that could prevent young people from feeling pressurised that they needed a form of literacy and provide an authorised view of mental illness to fit within an adult-led agenda.

1.5 Research aims and questions

The focus taken on challenging MHL and valuing the young person’s voice has led to the development of two overarching aims that have guided the enquiry process of this research. These aims guided the ARFGS (AR focus group sessions) and influenced the PRs when they conducted their own focus group sessions. My final research questions however were not finalised until the analysis stage was completed. This inductive approach ensured that the theory and knowledge related to my research would develop through an exploratory approach, and were not directed inappropriately to satisfy the principle researcher’s objectives (Flick, 2009).

The aims and questions of this research are set out below:

Aim 1: To explore young people’s understandings of psychosis

- **RQ1:** To what extent does a medically-constructed discourse around psychosis influence young people’s discussions about psychosis?
- **RQ2:** What sources of knowledge do young people draw upon in order to construct their understanding of psychosis?

Aim 2: To explore whether the concept of psychosis literacy is useful as the basis for educational interventions to improve young people’s educational and health needs

- **RQ1:** What are young people’s views about the concept of psychosis literacy?
- **RQ2:** What is the implication of young people’s views and how can these inform school-based education programmes?

The two research aims place a strong emphasis on appreciating young people’s understanding of psychosis and what knowledge and understanding young people express about this topic. It was important that these aims avoided any preconceived views about what young people are lacking in terms of their understanding, but instead needed to be exploratory and non-judgemental.

The open-endedness of these aims gave flexibility in the exploration of young people’s understandings, views, and beliefs, giving room for the young people to disagree or express concerns on the AR’s own interests or views. It was important that my aims did not prevent alternative meaning or understanding develop. Consequently, each PR-led group interpreted the topic of psychosis literacy with their own set of semi-structured questions reflecting their thoughts and opinions about this topic.

These aims clarified the need to learn, appreciate and value the knowledge and meaning young people have in their understanding of psychosis, thus challenging assumptions about young people’s illiteracy and stigmatising attitudes about psychosis. These aims realise that the meaning young people attach to psychosis will change according to different social interactions. Increasing our understanding of how this meaning changes will provide the opportunity to develop suitable psychosis literacy programmes that cater for young people’s literacy needs better.

1.6 Limitations

The first acknowledgement to make in this thesis is that even though a participatory approach was taken throughout the research, the topic choice did remain directed by the AR. There can be no claim made that the young people involved as PRs requested or wanted to research this topic, although they were interested in wanting to take part in this research and did formulate their own research questions and methods in the focus groups they conducted.

Secondly, young people were not involved in the analysis process of the research results discussed in this research study. The interpretation of the young person’s voice has remained the responsibility of the principal researcher. The reason the PRs did not continue in the analysis stage was caused by the student’s own academic demands limiting the amount of time they had to offer this research.

While this research hopes to make an impact on advancing the research evidence regarding psychosis literacy, it is unrealistic to believe that, without the co-operation of other health and educational professionals, the research evidence will have much influence on the decision-making process to alter the landscape of young people's mental health education curriculum.

There is an expectation that the research results will have the ability to inform adults, including educationalists, parents/carers, mental health professionals and politicians, what young people have felt they wanted or needed in relation to their psychosis literacy. For example, my findings have already contributed to the Government's inquiry into the role of education for children and young people's mental health (House of Commons Education and Health Committees, 2017). However, there are further political, economic, and social viewpoints that need further consideration before any form of change could occur. The bottom-up approach taken from the young persons' perspective will meet its challenges when facing an adult-orientated world.

The nature of the National Curriculum poses limitations on the role of psychosis literacy in a school environment. The importance attached to schools achieving benchmark results and successful Ofsted reports could direct the attention of schools away from initiatives such as psychosis literacy. It is foreseen that schools would resist any initiative, such as psychosis literacy, that would erode valuable teaching time that deters meeting National Curriculum/Ofsted requirements. For change to occur, wider reform is needed from a national level increasing the importance of developing a curriculum to suit the mental health needs of young people. Schools would then be more willing to value the implementation of psychosis literacy.

This research has also not considered what teachers', parents' or carers' views are about psychosis literacy. If teachers are not consulted, there is a strong possibility that schools may be unable or unwilling to facilitate these initiatives. Important questions remain unanswered surrounding the ability to resource such a programme, including whether it would involve increased teacher training or outside organisations to deliver the literacy programme. Questions will be raised whether these initiatives undermine valuable teaching time, placing more pressures on the teacher to meet targets and deadlines. Parents or carers could also raise potential resistance towards these literacy programmes, leading to the withdrawal of young people from these initiatives. Discovering from a parent/carer perspective what content and method of teaching about psychosis would be appropriate would help to address the anxieties adults have surrounding discussing psychosis with their children.

Lastly, this research has not considered the views and opinions of mental health professionals and service users. Service users' experiences are invaluable in the development of exploring the lived experience of psychosis within literacy interventions, while mental health professionals could supply insight into the services and support available and knowledge base behind the condition of psychosis. Their involvement would prove invaluable in the development of a psychosis literacy intervention.

Despite these limitations, one should not dismiss the young person’s voice. Instead, it is time to challenge the adult-orientated perspective towards what they believe is best for young people’s mental health educational needs. Adults may have well-intentioned concerns surrounding the nature of implementing psychosis literacy for young people, but these concerns may not reflect accurately the young person’s agenda. If we do not listen to young people’s needs at the start, how can one realistically satisfy the young person’s educational and health needs?

1.7 Outline of thesis structure

This introduction has intended to illustrate how my final research aims were set up. It has introduced some of the main theoretical concepts that have been problematised from my first ideas.

My literature review, Chapter 2, will next provide an overview of research attempts to understand young people’s understanding and knowledge surrounding mental health, and what school-based attempts there have been in addressing young people’s MHL needs. The outcome of this overview of the literature will demonstrate a gap in knowledge in neglecting young person’s views and opinions to influence future school-based psychosis literacy interventions.

Chapter 3 is dedicated to explaining the theoretical background of the main concepts that will be addressed and challenged throughout this research. This includes an academic discussion that surrounds the psychiatric understanding of Mental Illness. Then a discussion surrounding the value and complexity involved when interpreting lay understandings of Mental Illness. Finally the concept of childhood will be critically reviewed in order to challenge previous notions that have undervalued young people's position within society and has led to their voice being unheard.

Chapter 4 is where the methodology of this research will be explored. First a rationale of the use of peer research methodology will be commented upon and then followed by a detailed outline of the different phases of the research. Phase 1, the Adult researcher led focus group sessions. Phase 2, the peer research training sessions used to enable these young people to become peer researchers. Phase 3, the peer researcher focus group sessions. Finally, the choice of utilising a thematic analysis approach will be discussed.

Chapter 5 covers a joint analysis and discussion of my data. This chapter addresses the two main aims and research questions identified in this chapter. The themes generated in exploring Aim 1 revealed theoretical discussions related to biomedical explanations of the aetiology of psychosis, Haslam's (2005; 2007) folk psychiatry model and mental health stigma. Aim 2 exposed contrasting opinions to what young people felt should be the main aims and objectives considered within the psychosis literacy intervention.

Finally Chapter 6 is my conclusion. This chapter will provide a summary of the findings of the research. The findings overall showed an alternative interpretation of young people's existing knowledge and understanding of psychosis. This has allowed a further appreciation of what aims and objectives should be involved in future literacy interventions and how this could cater better for young people's needs. These findings would not have been obtained if not appreciated through the different methodological approaches utilised in this research.

Chapter 2: Literature Review

2.1 Introduction – rationale for literature review conducted

The aim of this literature review is to first examine how young people's knowledge and understanding of mental health has been assessed and evaluated. The reason for focusing on this type of literature is to consider what potential gaps there are in addressing young people's literacy needs. This is an important first step to consider what influencing factors are at play that will influence the type of literacy intervention. The way research has judged and assessed young people's level of literacy will be an important focus to justify a more social constructionist appreciation of young people's literacy.

My attention will then focus on the research literature which has evaluated existing school-based literacy interventions. The focus taken in this section will consider what potential barriers, criticism and level of effectiveness have been evaluated. Attention will question the rationale taken for the pedagogy approach utilised in these interventions. The reason for taking this focus is in hope that some common themed answers and guidance will inform what types of intervention have appeared to work or not work.

The last section of my literature review will finally consider the extent to which young people's views and opinions have influenced the implementation of literacy interventions. This is an area that this thesis intends to explore further, building further justification for increasing young people's involvement in the development of future MHL interventions.

2.2 What are young people's knowledge and understanding of 'mental health'?

In this section, my intention is to review the extent to which existing research literature has evaluated young people's level of knowledge and understanding of mental health. These attempts have made judgements about young people's level of literacy based on a criterion that fuels the belief that young people are stigmatising and illiterate. The nature of these concerns will illustrate the need to re-assess and re-evaluate young people’s level of literacy.

The type of terminology used in the literature reviewed has had a considerable influence on the portrayal of young people’s literacy. The term ‘mental health’ is problematic and wide-ranging in the literature and needs further critical analysis to understand young people’s interpretation. Close attention to the term ‘psychosis’ in this thesis will remain the focus of this literature review.

First, however, it is necessary to evaluate the two main factors traditionally tested by the research evidence on young people’s level of literacy. These factors are the influence of age and gender. The influence of age will be considered within the literature evidence in order to understand how literacy interventions should respond to age-related literacy needs.

2.2.1 The influence of age shaping children and young people’s knowledge and understanding of mental health

The influence of age has been a prominent factor explored when evaluating the extent of knowledge and understanding of mental health held by young people. The interpretation of older children having a more sophisticated understanding of mental health in relation to disturbance of thoughts and emotions needs further critical consideration (Wahl., 2002). Whereas younger children have been understood as lacking knowledge and understanding because they have lacked exposure to the experience or familiarity with mental illness (Fox, Buchanan-Barrow & Barrett, 2008; 2010) or have relied on more concrete explanations to understand mental health, compared to older children who can think in more abstract terms (Inhelder & Piaget, 1958).

Wahl (2002) however also showed that stigma levels increased with age and increased knowledge of mental health. It is naïve therefore to simply think that increasing awareness and knowledge about mental health or increasing life experience will be a panacea in reducing levels of stigma attached to mental health. Wahl (2002) however does point to the fact that in his literature review there was a lack of similarly standardised measurements of young people’s attitudes toward mental health illness. The variation in the language used when young people were asked about someone who was either ‘emotionally disturbed’ or ‘mentally ill’ may have an influence on the level of stigma generated. Meanwhile, more formal mental health terms may fail to reveal the attitudes of younger children who know mental disorder by more informal labels.

The approach whereby researchers interpret the language used by young people as examples of how mental health stigma has increased must be cautiously critiqued. For example, Jorm & Wright (2008) showed that older young people held decreasing levels of social distancing, and belief that the person is weak rather than sick decreased with age, but belief in dangerousness and unpredictability still increased. Measurements of stigma vary and need further context applied before understanding young people’s attitudes.

In the study by Spitzer & Cameron (1995) the researchers made comparisons between groups of thirty children in grades 1, 4 and 7 regarding their level of awareness of what mental illness is. The assessment criteria used involved comparing young people’s ability to acknowledge certain characteristics of people who are mentally ill, to differentiate between mental illness and mental retardation, to name various aetiologies of mental illness and to choose the right treatment modalities. The diagnostic medical criteria set by professionals to determine literacy has thus discredited younger children’s ability to know and understand aspects of mental health.

Similar studies were conducted by Fox, Buchanan-Barrow & Barrett (2008; 2010) where primary school children were recruited from Warwickshire and were divided into three groups: a ‘young’ group (School Year 2, 6 to 7 year-olds); a ‘middle’ group (School Year 4, 8 to 9 year-olds) and an ‘old’ group (School Year 6, 10 to 11 year-olds). The older eleven-year-old children acknowledged more psychological risk factors associated with mental health than the medical explanations provided by the ‘young’ group as contagious, short term and medically treated. Fox, Buchanan-Barrow & Barrett (2010) explained this difference as being because of younger children’s existing exposure to physical health conditions. The inability to distinguish the physical and mental domains of illness (Spitzer & Cameron, 1995;

Bailey, 1999) has remained a criterion to discredit the literacy of younger people as not having a clear understanding of what mental illness is (Wahl, 2002).

It is important to note that Fox, Buchanan-Barrow & Barrett (2010) did purposefully ask young people about their interpretation of common physical illnesses in parallel with mental health illnesses. These results are interpreted within a framework that does not represent accurately young people’s understanding. The conceptual framework used for analysing illness representations has focused on distinguishing between the identity, causes, consequences, curability, and timeline of an illness. The use of such conceptual frameworks could be misleading in the representation of young people’s illiteracy of mental illness by applying their knowledge of physical illness in the same context of mental illness.

Younger children have continued to be portrayed as not having a clear idea about what mental illness means, or an understanding of what specific characteristics are involved with mental illness (Schulze et al., 2003; Adler & Wahl, 1998). Schulze et al. (2003) primarily aimed at implementing an intervention to improve young people’s attitude towards schizophrenia, therefore it is not surprising the researchers do not give much credit to young people’s awareness. In Adler & Wahl (1998), 104 third-grade students in America (52 boys and 52 girls) lacked well-formed conceptions of mental illness as they were unable to provide specific examples of people with mental illnesses. However the Story Method used (showing the children three pictures of a man alone, a man with another man and a man with a child – then asked to tell stories of the man with a ‘mental illness’ ‘physical disability’ and ‘unlabelled’ group) neglects consideration how mental illness terminology can be confused and presents their lack of understanding from a specific medical model. Trained raters interpreted young people’s responses based on undesired attributes of mental illness often ascribed by adults. Interpreting young people’s responses from a specific adult interpretation potentially misrepresents young people’s attitudes towards mental illness.

In contrast, as children have grown older their concept of mental illness has grown in sophistication and understanding (Sedley, 2002; Wahl, 2002). In Sedley (2002) the sample framework involved four age groups of 63 young people (6-7, 9-10, 12-13 and 16-18) from two primary schools, one intermediate school and one high school in New Zealand. The young people explored their ideas about mental illness in focus group discussions involving three vignettes, each depicting a story about an adult with a mental health problem (schizophrenia, agoraphobia or depression). The older children clearly used more psychiatric labels than the younger participants, such as ‘schizophrenic’ and ‘hallucinating’, when describing the psychosis vignette. During the second stage of the study young people’s ideas about causes and treatments for mental illness were focused on, involving 36 of the children (aged 9-10, 12-13 and16-18) being interviewed individually and asked to explain why the individuals in the vignettes previously discussed had developed their mental illness and strategies to overcome their problem. The older young people again displayed more focus on the importance of ‘medication’, ‘therapy’ and ‘support from others’, as they referred to their recent life stresses. These interpretations illustrate again the importance attached to a criterion which conforms to a biomedical framework.

The ability of older children to think more abstractly and reflect on the relevance of mental illness is in accordance with Piaget’s theory of cognitive development (Piaget, 1968). Piaget’s theory, however, does not actually explain how children’s cognitive abilities develop, in terms of developing their understanding of mental illness. It is this explanation that requires further consideration within the aim of improving young people’s MHL needs. We must also be wary not to underestimate children’s abilities, and sometimes overestimate adult’s abilities, in terms of how we understand young people’s views and opinions about mental illness. More consideration of the wider context of young people’s external stimuli and individual experiences of their understanding of mental illness is required. Hatano & Inagaki (2000), for example, consider the more complex dimensions involved when exploring children’s conceptual development. It acknowledges that children are actively constructing the world that they perceive. The young person’s knowledge acquisition then develops and becomes more restructured as children perceive and experience more. The implication is that young people’s MHL needs need to consider the young person’s age and their personal and socio-cultural background.

There is also contrary evidence to suggest that younger children were able to relate to the wellbeing perspective of experiencing a mental illness, as younger children aged 5-11 have been found to supply clear, logical views of mental illness based on their own subjective experiences of physical illnesses. For example, the cause of schizophrenia and dementia was the result of brain damage (Fox, Buchanan-Barrow & Barrett, 2008). Similarly, children aged 10-11 compared mental health with any other physical health condition, ‘like if you got your arm in plaster, you break your arm its really obvious but mental health it’s a lot harder to see’ (Roose & John, 2003: p547).

Older children have also shown the ability to apply the experience of mental health illness to other people as well as reflect more concern for their wellbeing and personal identity than younger children (Mussen et al., 1990; Rutler & Rutler, 1993). The influence of growing up could have a positive impact on their understanding about the nature of mental illness, although it is also arguable that with increased age the formulation of stereotypes of mental illnesses can also develop. The reason put forward for this implication is because adolescents’ conception of personality traits also develops with age, allowing young people to associate mental illness with stereotypical personality characteristics (Flarell, Miller & Miller, 2001). It is incorrect to equate increased literacy of mental illness among older children with decreased stigma and stereotypes of mental illnesses. Instead, young children’s views may remain uninfluenced or infiltrated by the considerable amount of stigma that exists in the community and the media.

Hence, there is a convincing argument to utilise a more qualitative approach when exploring young people’s understanding of mental illness. Fox, Buchanan-Barrow & Barrett (2008) utilised semi-structured interviews and a card selection task to assess children’s responses to causes, consequences, timeline and curability of the different types of mental illness, while a focus group method approach was utilised in Roose & John (2003).

The credit awarded by researchers to young people for having the ability to understand some of the complexities surrounding mental health should also be brought into question. For example, twelve to fourteen-year olds in Armstrong Hill & Secker's (2000) study and ten- and eleven-year olds in Roose & John's (2003) study had the ability to name a variety of social risks such as bullying, parental difficulties, bereavement, and peer rejection as precipitating mental health difficulties. These young people conformed to professional beliefs of how mental wellbeing may be affected and displayed appreciation of alternative interpretations of wellbeing.

From a study in Sweden by Johansson, Brunnberg & Eriksson (2007), 18 younger teenagers aged 13 had difficulties in understanding the concept of mental health. However, the 30 older teenagers aged 16 were able to relate mental health more to internal feelings or emotions. These findings support Armstrong, Hill & Secker (2000) where 12-14-year-old children also had difficulty with the term ‘mentally healthy’. The ability of young people conforming to accepted understandings of abstract concepts was deemed an important criterion for literacy among professionals. Older young people had more developed emotional intelligence than younger children, increasing their ability to empathise and understand emotions better. Whereas the younger children in a study by Johansson, Brunnberg & Eriksson (2007) related mental health more to their relations with other people, including concerns about bullying with their peers.

Johansson, Brunnberg & Eriksson's (2007) work was focused specifically on considering gender rather than age differences and indicated that for older boys aged 16 neither friends nor family were more important, but when talking about school as a determinant, it was mostly related to friends. Therefore, it could be argued that gender is more influential than age. However, the bias towards a larger sample taken of older 16-year-old young people does not establish a clear judgement to be obtained regarding the influence of age in terms of understanding mental health.

Rees et al. (2008) confirmed the difference of opinion according to a representative survey of over 8,000 14-16-year olds in 2005 in comparison with a consultation exercise in 2007-8 with over 5,000 children from a ‘broader age range’ using research methods consisting of postcards, a website and focus group sessions. Rees et al. (2008) supplied no detailed age range, but responses reported involved younger children aged from 5-10. Their responses illustrated a difference in terms of the importance of pets, extended family, outdoor play, and toys as more influential factors affecting their wellbeing. Meanwhile, older children viewed relationships (including intimate relationships) as a more influential factor.

Younger and older children both have effectively demonstrated their differing thoughts about the factors that would benefit their health and wellbeing. However, the methods used by Rees et al. (2008) for the younger children in the consultation exercise do lend themselves to allowing younger children to explore their belief of wellbeing more so than survey methods used for the older children. More qualitative discussion among older young people could have revealed further discussion concerning factors influencing their wellbeing.

The appraisal of young people’s literacy about mental health is from a mental health wellbeing perspective rather than an evaluation of the understanding of mental health illness. Hence, the level of literacy that has changed due to age has resulted from a developmental change in young people’s emotional intelligence, and not necessarily from an increase in their understanding and knowledge related to mental health illness. Interpretations of young people’s improved literacy is more complex than portrayed in the literature in relation to the effect of developmental age. A more critical stance will similarly now consider the influence of gender on young people’s literacy.

2.2.2 The influence of gender on young people’s knowledge and understanding of mental health

The influence of gender has also existed as a tested factor within the literature concerning how it may influence young people’s views of mental health. There have remained strong conclusions from the literature reviewed that have tended to praise a girl’s level of literacy in comparison to boys. This literature review intends to consider what reasons have explained this difference, critically appraising how the literature has made this interpretation.

The identification of specific illnesses has been a strong criterion or measurement set by researchers to determine young people’s mental health literacy. A cross-sectional interview by Cotton et al. (2006) asked 1207 young Australians (539 males and 668 females aged between 12–25) to identify mental health difficulties using vignettes of characters experiencing mental health problems. Results indicated that girls were more likely to correctly identify depression than boys (Cotton et al., 2006). Similarly, Burns & Rapee (2006) concluded that Australian girls aged between 15 and 17 were comparatively more able to correctly identify signs of depression. The importance attached to Western psychiatry dominates discussion surrounding medical diagnosis and neglects the social construction of mental illness. Focusing on the social meaning and lived experience of mental illness could be more useful to discover the literacy of young boys in an alternative light, rather than just viewing them as illiterate.

The influence of gender has also been found in the likeliness of suggesting or accepting appropriate psychiatric support. Girls aged 12-15 were more likely than boys to endorse seeing a doctor or psychologist/counsellor for the treatment of psychosis and less likely to endorse using alcohol as a way of dealing with depression or suggest using antibiotics for dealing with psychosis (Cotton et al., 2006). Girls also expressed greater concern than boys over a depressed peer and understood that depression needs a longer recovery period than normal teenage problems (Burns & Rapee, 2006).

In Fox, Buchanan-Barrow & Barett's (2008) study, female participants expressed the need for more help and support for people with schizophrenia; boys instead focused their concerns on the effect that having schizophrenia would lead to them losing their friends. Concern about the wellbeing of the person with a mental illness was more prominent amongst girls than boys. This has been supported by previous studies demonstrating that girls held more concern that people experiencing a mental illness should not be socially excluded because of their illness and needed support to help them to seek appropriate help (Norman & Malla, 1983; Boldero & Fallon, 1995; Heights et al., 1998). Boys, however, were more concerned about the dangers that people with mental health illnesses had to society and were overall less benevolent or nurturing in their attitudes towards those with a mental health illness (Leong & Zachar, 1999).

Boys and girls also displayed different attitudes toward the importance of understanding mental illnesses. In Williams & Pow's (2007) study, a cross-sectional survey of 493 teenagers illustrated that boys reported lower levels of knowledge of mental health but were twice as likely to think they had enough education about mental health as girls. It might be anticipated that boys would be more resistant in engaging in MHL initiatives. Girls have also shown more understanding of topics of self-harm, suicide, depression and eating disorders to achieve the right support and advice. More boys, however, discussed the right for people to commit suicide and even toyed with the thought that suicide was a solution to certain people’s problems (Naylor et al., 2009). These views are concerning in relation to the Office for National Statistics (ONS) (2018) reports of higher male suicide compared to female suicide.

Williams & Pow (2007) showed the need to tailor towards boy’s literacy needs. However, no in-depth exploration has uncovered the reasons why boys were more resistant to being provided with MHL. These explanations could then inform professionals how to approach young people’s mental health literacy in a more relevant approach. Instead, the focus has been on providing a perspective of young boys holding more stigmatising attitudes towards individuals with mental illness. Meanwhile, females have reported more positive behavioural and cognitive responses to disordered peers during survey studies conducted in Australia and Scotland (Jorm & Wright, 2008; Williams & Pow 2007). The authors suggest that the reason for this difference was because boys had lower awareness and knowledge about mental health problems in general (Jorm & Wright, 2008; Williams & Pow, 2007). The MHL requirements advocated for boys included a specific focus to reduce stigma and increase self-help activity.

In Johansson, Brunnberg & Eriksson's (2007) study, Swedish boys aged between 13 and 16 were less willing to relate to mental health than girls, who would talk more about their self-esteem, self-confidence, the importance of good friends and being in love. Boys instead felt that it was more important to keep their feelings to themselves and viewed the importance of self-confidence and stability to be manly, tougher, and cooler. Mental health problems were not seen as characteristics of being macho, but as weak (Johansson, Brunnberg & Eriksson, 2007; Naylor et al., 2009). Fighting was an expression of negative emotions for boys compared with negative self-confidence and hopelessness for girls. Girls permitted themselves to express their feelings and seek help in contrast to boys (Johansson, Brunnberg & Eriksson, 2007). Boys reported having been more focused on the need to do well at school or in a sport as an influential factor on their level of self-confidence and feeling of wellbeing. Girls, however, focused more on the importance of body image than personal achievement (Armstrong, Hill

& Secker, 2000). Greater appreciation of different gendered views can enable wellbeing needs to be appropriately suitable for boys’ and girls’ needs.

Interpretations of boy’s illiteracy based on their inability to signpost individuals to mental health services to receive appropriate treatment, or because of their perceived lack of emotional literacy, does not give enough credit in exploring how boys socially construct their understanding and knowledge surrounding mental health. Lack of consideration or value is given towards alternative suggestions of receiving support or reasons why boys may feel that it may be difficult for individuals to access or acknowledge receiving official help. One reason for this was because the boys viewed the vignette in Burns & Rapee's (2006) study as relating to issues about their wellbeing rather than an illness. The lack of recognition between the seriousness of mental health wellbeing and mental health illness has been seen as a form of illiteracy, as the sixteen-year-old Australian young boys were described as failing to discriminate overt signs of depression with reasonable reactions of sadness when recommending whether professional help should be sought (Burns & Rapee, 2006). In fact, what the researchers do not appreciate is the lack of clarity and certainty that exists between the realms of mental health wellbeing and mental health illness. Boys' beliefs of mental health wellbeing need further consideration in relation to evaluating their mental health literacy, which may uncover an alternative meaning and explanation of how boys view mental illness experiences.

Plausible reasons for claims that girls are more sympathetic and sensitive compared with boys when considering mental health topics have been based on the suggestions that girls are naturally more intuitive in their emotional understanding, have greater personal experience with depression in both themselves and their peers or are more willing than boys to use psychological and emotional labels (Burns & Rapee, 2006). However, further exploration of the reasons behind the gender difference could supply a more insightful meaning and social construction towards how young people view mental health. The interpretation of being literate based on whether young people appropriately used psychiatric terminology and suggest what is deemed as appropriate support is too narrow a criterion. For example, in Ng & Chan's (2000) study 880 boys and 1,343 girls aged between 14 and 21 in Hong Kong illustrated a difference between the genders explained with the observation that the female students had more contact with individuals with mental illness. Personal circumstances appear influential in developing young people’s knowledge and understanding (Ng & Chan, 2000).

Nevertheless, one cannot avoid the concerns that these researchers have raised in relation to boys' attitudes to mental health and how this is having an impact on boys' access to mental health support. This problem needs to be acknowledged without unnecessary criticism against boys' levels of illiteracy. Working with boys' literacy about mental health and how they construct their knowledge and understanding will help professionals work with young boys to increase their understanding of mental health. No gender difference was noted in Cotton et al.'s (2006) work when the young people were considering the psychosis vignette, which questions the different level of understanding and knowledge that exists between diverse types of mental illnesses for both genders. It is important not to put forward blanket assumptions that problems remain over boys' literacy, and to assume what these differences in understanding might mean.

On reflection, one must acknowledge the influence of this gender difference on studies that have considered views of mental health from young people. In fact, it has been noticed that various research studies have acknowledged the difficulty of recruiting boys. For example, twice as many girls agreed to take part in the focus group and individual interviews in Armstrong, Hill & Secker's (2000) study. Researchers have suggested that the reason behind this gender difference is based on greater willingness and interest for girls to talk about mental health than for boys. The problem that arises is the fact that results of studies that have explored young people’s views of mental health are more from a female than a male perspective.

The dominance of focusing on the influence of age and gender as the main influences on exploring young people’s knowledge and understanding of mental health has resulted in a significant amount of concern directed at the level of illiteracy from an older, younger, or male young person perspective. It has neglected issues related to the language, social construction of mental illness or cultural influence involved in the dialogue young people are engaged in.

2.2.3 Concerns regarding young people’s MHL

Concerns have remained focused on how young people have learnt from an early age that mental health is a ‘personal failure’ and that it is acceptable to despise peers with mental health problems (Kirkcaldy, Eysenck & Siefen, 2004; Hayward & Bright, 1997). The Department of Health (2007) even concluded that young people have held the strongest discriminatory views against individuals with a mental health problem.

Hence health professionals have been concerned that such attitudes are detrimental to any help-seeking activity among young people, and have prevented young people effectively accessing mental health services, meaning that services may not effectively cater for children and young people’s mental health needs (NICE, 2009; WHO, 2003). There is increased responsibility on adults and professionals to ensure that the young person does not endorse these deeply-held attitudes before they take hold as the young person moves into adulthood.

There is still a dominant bleak picture painted of young people’s limited knowledge base and restrictive beliefs about mental health and appropriate mental health support (Armstrong et al, 1998; Bailey, 1999; Fox, Buchanan-Barrow & Barrett, 2008; 2010; 2010; Roose & John, 2003). Research has prominently discredited young people’s negative and stigmatising attitudes towards mental health (Bailey, 1999; O’Driscoll et al, 2012; Wahl, 2002). For example, young people have expressed negative views about the use of psychiatric medication. These are damaging findings in relation to the use of appropriate medical support, as young people have viewed the use of psychiatric mediation as potentially harmful and preferred to suggest inappropriate self-help and first aid techniques for conditions such as psychosis (Jorm et al., 2008; Lauber et al., 2001; Kermode et al., 2009 and Yap, Wright and Jorm, 2011).

The evaluation of young people’s limited knowledge and inappropriate beliefs has been determined by the values set by professional psychiatrists and educationalists. Little research has valued young people’s literacy without professional concerns surrounding the barriers that exist in allowing young people to access mental health services or reduce mental health stigma. This section of the literature review, however, intends to question how these adult and professional interpretations have prevented the opportunity to credit young people’s construction of their knowledge and understanding.

Discrepancies between children’s and adults' ideas about wellbeing have undermined child-centred interventions to cater for young people’s wellbeing needs (Sixsmith et al., 2007). An example which illustrates this concern occurred when interviewing a group of homeless young people using mental health services, all of whom expressed negative and stigmatising descriptions of the term ‘mental health’. This formed a major barrier in using mental health services; preferring instead to seek support from their family/friends (Sheffield, Fiorenza & Sofronoff, 2004). If the support received from them is inappropriate, the Mental Health First Aid (MHFA) obtained will not be adequate.

This adult concern and worry should not allow one to automatically jump to assumptions about young people’s stigmatising views regarding mental illness. It is important to examine young people’s views of mental health within a perspective that considers the complexity and multifaceted views of mental health. The dangers of misinterpretation from an adult perspective can prevent addressing important health and wellbeing issues for young people and use measures that are not meaningful to young people (Dex & Hollingworth, 2012). For example, adults have been pre-occupied in the research conducted with improving young people’s MHL in their aim to ensure mental health services improve for young people. This outcome neglects the aim of considering young people’s views and opinions about their educational needs to improve their level of MHL (Lindley, 2009).

In terms of providing young people with their MHL needs; it would be without real meaning or value for young people if correct information was simply supplied according to what adults felt would be most appropriate (Tones, Tilford & Robinson, 1990). Instead, listening to young people’s opinions and views can potentially help professionals to understand young people’s lives and determine if any intervention is actually required; it is inappropriate to assume or believe that professionals know what young people’s needs are. The real experts are the young people themselves (O’Reilly et al., 2013).

An example of an area of misinterpretation could be using mental health terminology with preconceived meanings attached by adult professionals without acknowledgement that young people may take a different interpretation. This shall now be considered in further detail by considering how existing literacy interventions have utilised different mental health terminology, and how this will influence the portrayal of young people’s level of literacy.

2.2.4 ‘Mental health’ or ‘mental wellbeing’ or ‘mental illness’?

The reason for the negative portrayal of young people’s views of mental health could be due to the tendency for research to focus on mental illness and not mental wellbeing (Secker et al., 1999). Even research that has tried to provide a more balanced and positive perspective of young people’s views regarding mental health wellbeing, such as Nadzeya, Bone & Dogra (2014), Dex & Hollingworth (2012) and Shucksmith et al. (2009), have still resulted in young people identifying mental health with mental illness. Researchers have attempted to use the term ‘positive mental health’ as the preferred justified terminology in health promotion to consider the health and illness perspective of mental health. Young people had difficulty focusing on the term ‘mentally healthy’, as they concentrated on only one of the words, either ‘healthy’ which was associated with being physically healthy or ‘mentally’ which was associated with mental illness (Armstrong, Hill & Secker, 2000). Young people equated the term ‘mental health’ with ‘mental illness’ and did not see mental health as relatable to their own lives, but were able to relate better to terms of feelings such as ‘sad’, ‘lonely’ or ‘depressed’ (Armstrong, Hill & Secker, 1998).

The confusion in mental health terminology needs more consideration when understanding how young people have distinguished between mental health and mental illness. When young people have been able to understand or identify with the specific behaviour with their own experience (direct/witnessed) they have been reluctant to label the behaviour as a ‘mental illness’ (Secker, Armstrong & Hill, 1999). The result has been young people not defining depression, for example, as a mental illness, because the experience encountered is part of everyday life, and they were able to relate depression to their or other's experiences (Secker, Armstrong & Hill, 1999). When behaviour is more familiar, fewer negative labels apply and it is less likely that young people define it as pathological (Schulze et al., 2003). Different mental illnesses are therefore understood differently, and contact with someone with a mental illness may act as a method of reducing stigma, as the young person becomes more familiar with the person behind the illness.

Young people have also shown confusion between ‘mental health’ and ‘learning disability’ (Nisha et al., 2005; Rose et al., 2007; Bailey, 1999). Out of the 116 words used by young people as ‘popular derogative terms’ to describe mental health, 38 words were related to descriptions of physical and learning disabilities (Rose et al., 2007). Similarly, in another survey with young people, words such as ‘spastic’ represented 14.52% of responses, ‘retarded’ 19.04% of responses and ‘peculiar’ 6.66% of responses to describe mental health (Bailey, 1999). Young people’s views of mental health could easily be confused within the type of terminology used, and assumptions from adults that young people understand what these terms mean is not necessarily true. Hence misconceptions of how certain mental health conditions are related to learning disability conditions could influence the nature of stigma attached to mental health.

A focus on mental health wellbeing in the research literature could have a different effect on how young people have formed meaning attached to this term. This shows the importance of gaining a deeper contextualised understanding of the meaning related to terminology used by adult professionals from a young person’s perspective.

2.2.5 Mental ‘wellbeing’

In the UK, the research literature has highlighted that young people hold different views on behaviour that they interpret as not a mental illness but apart of their own general wellbeing. Young people’s views have been praised as being much more positive when engaged in a discussion about mental health wellbeing and have been credited as showing overall good knowledge and understanding.

In Roose & John's (2003) study, young people viewed mental health within the perspective of physical health, involving thoughts and behaviours that ensured peace of mind for good Mental health. The effect of focusing on mental health wellbeing rather than illness had the effect of reducing young people's stigma attached to mental health. Hence, young people had the ability to understand and appreciate the meaning of mental health in terms of their wellbeing without signs of stigma. More credit should be given to listening to young people's views and opinions about mental health, without preconceived adult fears that young people have more stigmatised views and lack of MHL. However, contextually, in Roose & John's (2003) study the young people were aged 10-11-year-old. Hence, age could be a significant factor when interpreting and understanding mental health within the wellbeing framework.

One problem acknowledged when considering the concept and meaning of young people's wellbeing is the fact that most definitions are usually adult conceptions that mediate our understanding of the child's wellbeing and not the child's own construction of wellbeing (Sixsmith et al., 2007). In contrast with adults' beliefs of wellbeing, young people in one study attached more importance to 'neighbours' in their role within the community and placed the 'church' and 'fun' as central features affecting their level of wellbeing (Sixsmith et al., 2007). Young people's contribution towards understanding the importance and relevance of their mental health wellbeing should not be under-estimated.

Young people have explored the multi-dimensional and complex nature of the concept of wellbeing through the relationships they have formed with their friends and family, the influence of their environment and level of freedom (Dex & Hollingworth, 2012). Similar findings described in Armstrong, Hill & Secker (2000) considered the importance of family and friends, people to talk to, personal achievements and feeling good about yourself to become mentally healthy. From these views for young people, positive self-concept and sense of belonging and support were fundamental needs to ensure adults respond to supporting young people's feeling of safety and be able to trust an adult to talk to (Armstrong, Hill & Secker, 2000).

The main problem found in young people's perception of their wellbeing was their belief that it was not important enough to trouble others regarding their wellbeing needs compared with adults' problems (Armstrong, Hill & Secker, 2000). In response, adults need to value and take young people's wellbeing needs more seriously, as young people have expressed that they have felt that their concerns were trivialised by adults (Naylor et al., 2009). Young people have therefore reported that they do not know how to talk about their mental health wellbeing issues, as they feared that admitting that there was a problem will make them different (Potts, Gillies & Wood, 2001). To rectify this belief, Potts, Gillies & Wood (2001) advocated young people should be made aware that mental health and wellbeing does not mean mental illness, which could lead to feelings of being stigmatised.

Hence, it is expected that when utilising the term mental illness with young people there will be an increase in stereotypical and stigmatising attitudes in relation to the labels used to describe these experiences. An overview of these findings shall now be explored.

2.2.6 Mental ‘illness’

In Rose et al.'s (2007) study the researchers showed the use of stigmatising and confused labels used by 14-year-old school students in England when referring to people with mental illness. From the analysis of the 250 labels used by young people, the researchers concluded that young people lacked information and have strong negative emotions attached to mental illnesses. Similarly, Bailey (1999) found 106 young people aged 11-17 citing several derogatory phrases and terms including ‘psychopath’, ‘nutter’ and ‘lunatic’.

Interpreting these labels as representative of young people’s own beliefs is not necessarily correct. There is a lack of appreciation within current research about how young people have constructed these terms when describing someone with a mental health condition. The automatic reaction from a professional perspective is to find the use of these terms as inappropriate and stigmatising without taking consideration the context how and why these terms are used.

The use of labels to describe mental illness is understood as inappropriate in terms of fuelling stigmatising attitudes (Gove, 1975; Jorm & Griffiths, 2008; Link et al., 1989; Pescosolido et al., 2010; Scheff, 1966). Mental illness for young people has been defined as behaviours that could not be identified or related to and legitimised as abnormal through reference to media representations (Secker et al., 1999). Not being able to relate to mental illness has made it harder for young people to talk about mental illness labels (Armstrong, Hill & Secker, 2000).

The problem of learning from an early age that mental illness is an indicator of personal weakness or personal failure (Kirkaldy, Eysenck & Siefen, 2004; Hayward & Bright, 1997; Naylor et al., 2009) indicates the social and cultural underpinnings that young people are exposed to when equating weakness with mental health illnesses. Historically, the blame of personal weakness or failure has been a key influence forming attitudes towards those with a mental health illness. The experience of psychosis, for example, was someone who was demon-possessed without sufficient moral backbone to hold off Satan (Kinzie, 2000).

Young people most commonly perceive the causes of mental health illnesses to be related to the individual’s social environment and personality (Link et al., 1999; Matschinger & Angermayer, 1996). The individual again is blamed as part of the cause of the mental health illness, which may support the theory that young people are keen to disassociate themselves with possible mental health risk factors, and do not want to think that mental illness could happen to them.

The result of this blame has been the reported incidences of young people despising their peers with a mental health illness with feelings of guilt, shame, and denial, leading to the use of mockery, pejorative terms and social exclusion (Naylor et al., 2009). This is because mental illness has links with the attribution of responsibility of individuals with a mental health illness choosing to behave as they do (Hayward & Bright, 1997). The diagnosis of ‘social phobia’ for example is a sign of personal weakness in terms of not being a real illness (Reavley & Jorm, 2011).

There is however also contradictory evidence to suggest that most psychiatric labels were associated by young people as being sick and not weak, which helped promote help-seeking behaviour (Wright, Jorm & Mackinnon, 2012). Reference was made to the accurate labelling of psychosis, which made young people view seeking psychological therapy, antipsychotic medication and counselling as most appropriate sources of treatment options. In contrast, lay labels such as ‘stress’, ‘paranoid’ and ‘shy’ reduced the likelihood of seeking help (Wright, Jorm &

Mackinnon, 2012). It is important therefore not to assume that young people will stereotype specific mental illnesses, but instead acknowledge the value of exploring young people’s understanding of specific mental illnesses to increase their understanding of how to deal with the illness.

In a study by Secker et al. (1999) 102 young people from four Scottish high schools were involved in focus group discussions (with 18 individual interviews) that used five vignettes describing five different mental health portrayals. The result of the study illustrated that young people had less sympathy when relating mental illness vignettes on adult characters than the young people characters. Young people were able to relate to the vignettes of younger people better, as illustrated in the contrast between the adult and young people experiencing psychosis in the vignettes. The young person with psychosis was explained by the young people through an exploration of their own personal experiences, thinking that there are monsters under the bed (Secker et al., 1999). However, the age of the young people involved in this study is not known; this makes it difficult to appreciate the influence that age has had on these young persons’ views. What would have been interesting to find out would be whether the older the young person is the more they are able to relate to the experiences of adults' mental health problems.

The use of celebrities or shared stories has been a method utilised to reduce young people’s stigma of mental illness (Corrigan et al., 2012; Couture & Penn, 2003; Pettigrew & Tropp, 2006). Results have shown an increase in the level of tolerance and empathy towards the individual’s experiences. The illness no longer remains an alien concept, but young people are able to view the illness from a personal perspective.

The inability of young people to recognise mental illness in surveys conducted has also been a concern. In Wright et al. (2006), just over half of 600 young people aged 12-25 years were able to identify depression, but only a quarter were able to identify psychosis in a vignette provided during a cross-sectional telephone survey. There were also differences illustrated when comparing psychosis and depression with help-seeking issues, which illustrates the potential for more stigma towards psychosis than depression.

In the United States, a study by Watson et al. (2004) considered 1,566 middle school students (grades 6-8) who showed prior to taking part in the curriculum *The Science of Mental illness* that they had some understanding of mental illness as a problem with the brain, with biological or psychological causes. There was still however obvious lack of knowledge on the possible treatment options available and aspects of the mental illness concerned.

There has been neglect in the research conducted to investigate how young people refer to mental illness and the terminology used in relation to mental illness (Fox, Buchanan-Barrow & Barrett, 2008). The use of a wide range of terms of ‘mental illness’, ‘mental disorder’ and ‘emotional distress’ are used without adequate knowledge of young people’s attributes to these words. Fox, Buchanan-Barrow & Barett (2008) therefore approached the exploration of mental illness in terms of showing the children, aged 4-11, vignettes of four mental illnesses (depression, anorexia nervosa, dementia, and schizophrenia) all experienced by a female adult. The use of diagnostic labels and vignettes describing the behavioural symptoms of mental illness have been understood as a more suitable and valuable method in understanding children’s conception of mental illness, rather than focusing on mental illness in general terms (Fox, Buchanan-Barrow & Barrett, 2008). The benefit of this approach is that the research conducted can avoid obtaining potentially too wide and general views of mental illness, and instead supply a correct understanding of young people’s specific views about specific mental health illness disorders and enable a greater analysis of the difference between different mental illnesses. This is because the extent of stigma held by young people will differ according to different disorders (Crisp et al., 2000). However, Fox, Buchanan-Barrow & Barrett (2008) have specifically adapted the vignettes explored to suit the age group of children aged 4-11, and they cannot apply to younger people aged 15. The terminology used to explore young people’s understanding of mental illness needs further exploration for older young people.

From this literature review, there is a significant amount of concern that the use of labels of mental illnesses can increase young people’s level of stigma. The result has been negative attitudes held by young people towards seeking help or treatment for the experiences of mental illness. These attitudes shall now be explored in the next section.

2.2.7 Attitudes towards seeking help or treatment for mental health illness

There have been significant concerns reported of young people not wanting to or delaying seeking help about mental illnesses (Marshall et al., 2005). This was because of the lack of trust, fear, or stigma in receiving professional support. Instead, young people have preferred to turn to their friends for help rather than professional support (Burns & Rapee, 2006; Jorm & Wright, 2007).

The negative attitudes towards mental health professional support have placed barriers towards the creation of accessible mental health services for young people. Young people have perceived children and adolescents mental health services (CAMHS) as being ‘shrouded in mystery’ (Naylor et al., 2009). This level of mystery has only increased the amount of fear and doubt for young people in obtaining or acknowledging the type of help or treatment provided by CAMHS.

Instead, the support young people turn to has been understood as inappropriate or even harmful for the recovery of a mental illness. Young people have been portrayed as less likely to appreciate the extent of the problem of mental illness among their peers, which may be due to young people being less willing to identify mental illness with their peers (Bowers et al., 2013). The consequence could be denial, avoidance, or lack of appreciation of the seriousness of the mental health concerns of young people. It is important that young people’s ability to recognise and identify specific mental illnesses is improved to ensure that the correct help and support is provided.

To improve this level of support, it has been found that if someone from the young person’s social network suggests to their peer to seek professional support, the young person would be more likely to seek that source of professional support (Cusack et al., 2004). Young people’s social networks have a considerable influence on young people’s attitude toward seeking help and support. The responsibility for young people to support their peers and friends in relation to their mental health needs is invaluable in supporting the aim of literacy programmes to direct young people to appropriate mental health services.

Particularly negative and resistant views have been expressed by young people against the use of psychotropic medication (Angermeyer & Matschinger, 1996; Jorm et al., 1998; Priest et al., 1996). Young people have instead suggested inappropriate self-help techniques to help those with psychosis (Jorm et al., 2008; Lauber et al., 2001; Kermode et al, 2009). Such anti-medication attitudes have focused on the treatment of psychosis rather than any other mental health illness. Improving MHFA for psychosis can lead to an improvement in the level of support that is provided among peers and friends.

Specific focus will now turn towards considering how the literature reviewed has portrayed how young people have reacted to the term ‘psychosis’. This is an important consideration, as this thesis focuses specifically on using the term ‘psychosis’ with young people.

2.2.8 Young people’s views of ‘psychosis’: The influence of terminology used

There is substantial literature that shows that psychosis is one of the most stigmatised mental health illnesses in terms of its links with violence, dangerousness, unpredictability (Taylor & Gunn, 1999; Jorm & Griffiths, 2008; Jorm & Wright, 2008; Wright, Jorm & Mackinnon, 2011). Compared to other mental illnesses, psychosis has more negative connotations, with greater desire and need for social distancing (Wright, Jorm and Mackinnon, 2011; Secker et al, 1999; Reavley & Jorm, 2011; Arbanas, 2008; Angermeyer et al., 2004). For example in the UK, in comparison with Canada, young people aged 14-16 were less aware that schizophrenia was not a split personality and that it is a myth that people with schizophrenia are more likely to be violent than the general population (Pinfold et al., 2005). Such a contrast in the level of stigma shows the need to examine more specifically what young people’s views are about psychosis.

The ability of young people to identify psychosis or schizophrenia did not have any benefits in terms of the aims to provide anti-stigma interventions. For example, Wright, Jorm & Mackinnon (2011) telephone surveyed 2802 Australians aged 12–25, and results showed that the ‘dangerous/unpredictable’ component was predicted most by the labels ‘schizophrenia/psychosis’ in contrast to the vignettes of a young person experiencing depression or social phobia. The difference of belief about dangerousness attached to schizophrenia but not depression continues into adulthood, as illustrated in a survey to 3998 adults by Jorm & Griffiths (2008).

The interpretation of the surveys described previously specifically choose to contrast ‘psychosis/schizophrenia’ with ‘depression’. The choice for such a contrast illustrates possible preconceived assumptions that young people will draw a contrast between these different mental illnesses. This will obviously alter young people’s views and thoughts about psychosis in view of other mental illnesses. Careful discussion about ‘psychosis/schizophrenia’ is instead required, which does not lead young people to appear more stigmatising towards psychosis. It is also important to note that the level of stigma is not unique to young people, but can exist into adulthood.

The fact that psychosis or schizophrenia has appeared to generate more stigma than other mental illnesses has led to the conclusion that discussing these conditions is not right in young people’s MHL programmes. Professional and adult concern about the vulnerability of young people is significant, as there is fear that raising these mental illnesses will automatically create negativity and fear towards mental illness and not promote an anti-stigma agenda. The problem with this paternalistic agenda is that it neglects consideration of what young people want and actively prevents a discussion focused on these terms due to a perceived taboo. If, however, there was a more open discussion, the level of taboo surrounding this topic may reduce.

As discussed previously, this research has utilised the term ‘psychosis’ as preferable to a specific diagnostic criterion used for ‘schizophrenia’. This will allow and broaden the discussion of the nature of psychosis. However, the term ‘psychosis’ is also less well known than ‘schizophrenia’ (Addington, Berzins & Yeo, 2012). The use of formal medical terminology risks the potential failure of revealing young people’s views. The researcher needs to acknowledge the influence that such terminology can have on the research and try to speak in a language that young people will understand when exploring the meaning of mental illness (Wahl, 2002; Fox, Buchanan-Barrow & Barrett, 2008).

The term ‘schizophrenia’ however also has been further confused by young people in relation to its literal interpretation as the characteristics of being a ‘split personality’ or ‘split mind’, as illustrated by research studies conducted in Greece, where the Greek translation of schizophrenia was ‘split personality’ (Economou et al., 2014; 2012). In other countries, such as the UK, this direct translation is not as obvious. However in a German survey by Schulze & Angermeyer (2005), a fifth of responses (18.8%) from 293 young people aged 14-18 (18.8%) confirmed that they did characterise someone with schizophrenia as having ‘two faces’, a ‘split self’, having ‘two personalities in one body’, ‘leading two lives without knowing of the other’ and ‘a mental conversion into a person that one desires to be’. These responses raise significant concerns about how young people are misinterpreting the nature of the illness, especially when 20.5% of the young people had no idea of what schizophrenia was (Schulze & Angermeyer, 2005).

The terms ‘psycho’, ‘schizo’, ‘schizophrenic’ and ‘psychopath’ were particularly prominent in one study by Rose et al. (2007), all of which appear to be related to the condition of psychosis. Four hundred young people aged 14 were involved in this study in five secondary schools in England. The term ‘psycho’ was one of the most frequently mentioned words used (the frequency was 10 times) out of the 250 words and terms used to describe someone with a ‘mental health problem’. The category the researchers grouped this term under was ‘popular derogatory term’, blamed on the influence of the media (Rose et al., 2007).

Unfortunately, Rose et al. (2007) did not allow the young people to explore what their meaning of this term relates to, meaning they were unable to explain or defend their meaning of using this term. Instead, the research focuses specifically on the discovery of presumed stigma among young people. However, there is a strong possibility that the term ‘psycho’ does not relate to the experience of psychosis, but describes a ‘psychopath’, and the violence and aggression displayed by someone with a psychopathic personality disorder. The degree of confusion rather than stigma involved in terminology used needs to be explored further. Depictions of mental illness in children's media in a study by Wahl (2003), for example, have illustrated a rare use of medical or professional labels, but slang terms such as 'psycho'. Therefore, the interpretation of 'psycho' is not necessarily related to psychosis.

The main reason put forward why young people have held these misinformed stigmatised views of psychosis is because young people receive more information about mental illness from the media than any other source; it is one of their chief socialising agents (Wahl, 2002). 63.6% of young people surveyed in a study by Schulze & Angermeyer (2005) stated that they obtained most of their knowledge from media imagery (63.6%), dominated by the influence of TV (51.7%). It is this media coverage that has presented overt discrimination and representation of mental illness confined to people with psychosis; portraying psychosis as dangerous and violent, with common terms of 'schizo' and 'nutter' used in advertising, film and everyday language (Schulze et al., 2003; King, 2004; Wahl, 1992; Taylor & Gunn, 1999). Reports have found that 70% of villain characters in children's media with a mental illness were portrayed as more graphic and frightening than other non-mentally ill villains (Signorielli, 1989). Media references of mental health continue to be often negative in terms of being unattractive, violent, and criminal, thus using mental health to disparage and ridicule (Wahl, 2003; Wahl et al., 2003; Wilson et al., 2000). Content analysis of British TV and press output illustrated that most media messages drew heavily on split personality misrepresentation (Philo, 1996). The media has a strong role in legitimising young people's conclusions of their views on mental health (Secker et al., 1999).

Young people have mirrored the socially accepted fear associated with psychosis in terms of entering relationships, renting, recommending a job or looking after children (Angermayer & Matschinger, 1995; Angermeyer & Schulze, 2001). This general feeling of worry, caution and fear does not allow or give young people the chance to be able to relate the experience of psychosis with their own experiences (Secker, Armstrong & Hill, 1999; Schulze et al., 2005). Psychosis is perceived as a severe mental illness that remains in the realms of the imagination.

In contrast to these negative views from young people, there needs to be a word of caution in highlighting these views as being more stigmatised than adults' perceptions of psychosis or schizophrenia. One in three adults, for example, still relate schizophrenia to a split personality (Holzinger et al., 1998; Stuart & Aboleda-Florez, 2001). There are also less derogatory and negative personalised comments made by young people compared with 10% reported among the general public (Angermeyer & Metschinger, 1995). Instead, Schulze & Angermeyer (2005) acknowledged that German young people aged 14-18 showed more raised awareness of schizophrenia being an illness compared with adults' beliefs of schizophrenia. In fact, more credit and the prospect to improve and change young people's views of psychosis should be offered, rather than focusing on blaming young people for holding stigmatised views.

It has overall been illustrated that there is a specific difference in young people's views of different mental illnesses; psychosis has been more stigmatised, misunderstood and less well known or identified. Hence, more focus should directly consider young people's views of psychosis. At the same time the literature considered has utilised the terms 'psychosis' and 'schizophrenia' within a framework directed towards reducing levels of stigma attached to this label, rather than focusing on the actual meaning that is attached to the lived experiences related to this illness.

2.2.9 Social construction of mental illness – influence on 'stigma'

It has become clear from the literature considered that stigma is reduced when young people can relate to mental illness as part of their wellbeing. Whereas if mental illness is viewed as an alien experience, the stigma will increase, as young people are unable to relate to such experiences.

In Secker et al. (1999) 102 Scottish young people took part in 17 focus group discussions and 18 young people were interviewed individually to explore their understanding of mental illness. Secker et al. (1999) concluded that if the young people could understand or relate to the behaviours described in the vignettes the young people were reluctant to label these experiences as mental illnesses. Conversely, behaviours they could not be related to were constructed as abnormal and labelled as a mental illness, which was legitimated through reference to media representations.

The implication of Secker et al. (1999) is that there is a different view taken by young people about different mental health illnesses. It seems therefore unlikely that young people would be able to name or relate to the nature of psychosis. This supplies an explanation why psychosis is more stigmatised than other common mental illnesses. However, in a survey of 293 German young people aged between 14-18 more credit was given towards the lack of stigma the young people associated with the word ‘schizophrenia’ in comparison with the general public (Schulze et al., 2005). Is it possible that professionals should not dismiss young people’s ability to relate to the condition of psychosis.

Only one in five young people in a study by Schulze et al. (2005) connected schizophrenia with split personality. Derogative terminology of ‘crazy’, ‘nuts’ or ‘madness’ was hardly used and negative personality characteristics such as unpredictability, violence and delinquency were not associated with schizophrenia. Young people associated schizophrenia with a mental health illness or problem (Schulze et al., 2005). The consequence of this different construction of schizophrenia enabled the amount of stigma and discriminatory attitudes to decrease. However, one must also appreciate the German linguistic and cultural differences in this research study while utilising clinical terminology. The cultural dimension that language involves should also be appreciated when assessing young people’s understanding of mental illness.

2.2.10 Cultural influences on young people’s understanding of mental illness

From a Western medical psychiatric model, the diagnosis of psychosis or schizophrenia has created a framework to determine the construction of young people’s stigmatised views. From alternative cultural perspectives, there is evidence to suggest that young people’s views are shaped differently according to their culture.

In Stone & Finlay’s (2008) study 128 young adults from London colleges completed a questionnaire assessing stigma beliefs, symptoms of mental illness and help-seeking beliefs in response to symptom vignettes. The findings showed that African-Caribbean participants were less stigmatising than White European participants to the diagnosis of schizophrenia. The reason this may be the case has been speculated by the researchers as that African-Caribbean participants were less likely to label the symptoms of the vignette as mental illness, despite reading the vignette describing the psychologist diagnosing schizophrenia. African-Caribbean participants were less familiar with the term ‘schizophrenia’ and distrusted the psychiatric opinion as being ‘white’. The participants preferred to seek non-medical support from the police (due to their experiences of racism). However, Stone & Finlay’s (2008) study does acknowledge that the generalisation of White European participants does not just include those from a British background and, similarly, African-Caribbean participants included different Caribbean and African diversity, which does not consider how long the participants have lived in the UK. These factors will have an influence on the views they hold about the nature of schizophrenia. There is also no detail provided on the age of these participants, other than they were aged ‘16 and over’. This could then have a further influence on their beliefs of schizophrenia and does not relate directly to the age group of young people at secondary school.

Pathogenic conceptualisations were also perceived to be confused by 15 Gujarati young people aged between 11 and 16, particularly the terms ‘mental health’, ‘mental illness’ and ‘learning disability’ (Dogra et al, 2005). However, this interpreted failure and inability of young people to define the concept of mental health needs to be reviewed. In fact, mental health is wide ranging with multiple meanings and realities for different people. The sliding scale of mental health wellbeing and illness is not as clear and straightforward as some professionals have interpreted. The Western psychiatric interpretation of mental health neglects, for example, the cultural diversity that existed within the Gujarati community that Dogra et al. (2005) have tried to explore. Hence cultural influence on young people’s attitudes and knowledge of mental illness requires further consideration.

The researchers in Rahman et al. (1998) conducted a MHL initiative in Pakistan where five common mental health disorders were depression, epilepsy, psychosis, drug dependency and mental retardation. In contrast with a Western diagnostic classification the distinction between mental health, learning disability and even physical health conditions such as epilepsy is blurred. Rahman et al. (1998) however illustrate the need to acknowledge the cultural complexity involved when interventions intend to improve MHL. This questions what criterion determines literacy within diverse cultures where the understanding of mental health differs from a dominant Western diagnostic framework.

Moreover, it is not only an international cultural influence that can shape young people’s discourse surrounding mental illness. Young people’s own subculture also has a key role in shaping the meaning held behind the labels of mental illness explored previously. The problem attached to exploring this meaning is that it is particularly difficult to access as an outsider.

2.2.11 Youth subculture

The influence of the media is well-documented, and discussed in section 2.2.8, as having a significantly negative effect on the imagery associated with psychosis. This has only encouraged stigma and prevented help-seeking behaviour to occur. However, there is evidence to support the positive role the media can provide to young people through the creation of their own subcultures.

In Scott & Chur-Hansen's (2008) study, in-depth semi-structured interviews to nine Year 10 students from a rural Australian secondary school (two boys and seven girls) showed the influence youth subculture and SMS text messaging can have on young people’s mental health. Reference made to ‘emo’ subculture within the context of learning about depression, showed that the influence of subculture can encourage the overt demonstration of emotions. The young people shared the same feelings of misunderstanding and experienced similar self-harming behaviour. Thus, the social construction of the experience of mental health has turned away from the field of psychiatry into a form of identity within the ‘emo’ subculture.

There is acceptance in Scott & Chur-Hansen's (2008) study that there is a requirement to conduct more research about the influence of subcultures on young people’s behaviour. One question remained whether such youth subcultures supply a positive or negative influence on seeking help and support. Nevertheless, the interpretation given by youth subcultures is important when considering its impact on young people’s MHL.

The young people in Scott & Chur-Hansen's (2008) study did specifically mention the benefits of using SMS text messaging to communicate and confide in someone to receive less confrontational help related to their mental health. The influence of youth subculture and the development of technology requires further consideration when considering meeting the MHL needs of young people. The use of social media, for example, is a topic not explored enough with young people. The fear of the influence of youth culture and associations with pro-anorexia and pro-self-harming websites has outweighed any consideration given to the influence social media has had in developing young people’s literacy awareness.

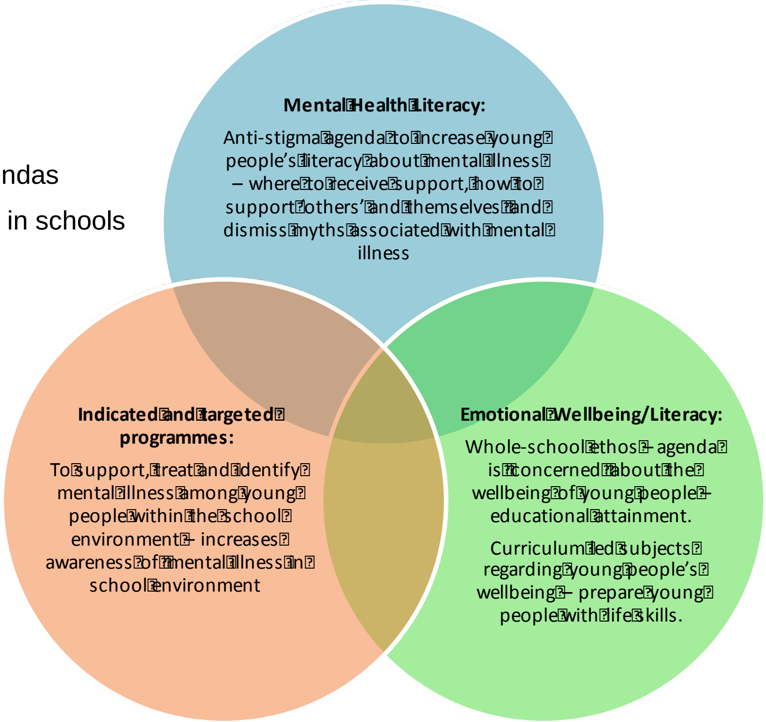
The next section of my literature review will consider what role the school environment has had in teaching young people about mental health. These interventions will respond to the concerns raised in this section about young people’s level of stigma and lack of help-seeking behaviour.

2.3 How have UK schools traditionally approached teaching young people about mental health wellbeing/mental health illness?

Teaching young people about mental health wellbeing/illness exists between the agendas of different professional worlds: mental illness intervention (psychiatry), mental health problem prevention (public health) and mental health promotion (health promotion and health education) (Nind & Weare, 2009).

There is an overlap between these professional agendas that will be examined in this literature review, but what has been recognised is that a holistic approach is missing, and the young person’s voice has been lost or neglected. The intention of this literature review is to show how UK schools have approached teaching about mental health within these different dimensions. I have created the following Venn diagram to illustrate an overview of the different aims within UK schools considered within the literature:

Figure 2: Overlapping agendas for teaching Mental health in schools



2.3.1 Mental illness in schools: indicated and targeted programmes

Teaching and learning explicitly about mental illness in UK schools is relatively uncommon within the National Curriculum as an educational initiative. It has remained the responsibility of mental health services to tackle mental illness through specific mental illness prevention programmes. These programmes aim either to recognise mental illness among young people (targeted) or identify young people with potential mental health problems (screening). The focus is not concerned with the *general* needs of increasing young people's knowledge and understanding of mental illness.

The Targeted Mental Health in Schools (TaMHS) initiative, for example, aimed to respond to the needs of young people found as being at risk of developing mental health problems (Davidson, 2008). This initiative supplied the opportunity for the school to become a potential hub for more integrated work between health and educational professionals to increase access of mental health services to young people (Wolpert et al., 2013). Support focused on ensuring that such provision could 'immunise' them from later difficulties (Memell & Gueldner, 2010).

One consequence of screening or targeted approaches in schools is that it has entered teachers into the role of mental illness prevention. In fact, teachers became ‘Tier 1 CAMHS workers’ to notice and respond to signs of mental illness in the pupils they teach (Davidson, 2008). Future in Mind (DH, 2015) continues to direct the vision for 2020 to ensure that all who work with young people will be trained about mental health and know how to support them. The focus has centred on improving access to support within the school, as teachers now have non-statutory guidance showing the importance of providing a counselling service for young people in schools (DfE, 2016). The Government Green Paper ‘Transforming Children and Young People’s Mental Health Provision’ (DH & DE, 2017) has also proposed changes to support schools manage young people’s mental health through the introduction of a designated mental health lead and by introducing mental health support teams to increase collaborated support to those young people with problems with their mental health.

Concerns related to psychosis within the school environment have been minimal. A predominant focus has remained on targeting more common mental health conditions (DH & DE, 2017). However, Yung et al. (1996) have argued the need to set up a targeted screening initiative to prevent young people at risk of mental health status (ARMS) from developing psychosis later in life. Early intervention services have therefore increasingly been involved in schools to detect ARMS warning signs, psychotic-like experiences that may lead to the development of the symptoms of psychosis. These include ‘prodromal’ symptoms of reduced concentration, attention, reduced drive and motivation, anergia, depressed mood, sleep disturbance, anxiety, social withdrawal, suspiciousness and deterioration in role functioning (Yung et al., 1996).

Indirectly, such initiatives could increase awareness among young people about mental illness in schools. Exposure to the fact that their peers have mental illnesses and that support is obtainable within the school environment should open the possibility for young people to discuss mental illness. There remains no clear aim within these initiatives to improve young people’s knowledge and understanding of mental illness. The decision has been made in this literature review not to focus on such initiatives, but instead acknowledge and show awareness that most research and policy direction about mental illness in schools has remained enclosed within indicated and targeted programmes. The aims of these programmes have been health- rather than education-orientated.

In applying this exception to my literature review, the results have shown that universal school-based interventions have taught mental illness/wellbeing either as one-off small-scale anti-stigma MHL interventions or have embedded the teaching within the school's curriculum or ethos, focusing on young people's emotional wellbeing/emotional literacy. These mental health promotional initiatives vary in motive and approach.

2.3.2 Teaching about mental wellbeing in a whole school context: Embedded ethos within UK schools

There has been a general neglect in considering the need to teach young people about specific mental *illnesses* in schools. Instead, schools have increasingly acknowledged the relevance of being concerned about young people's mental *wellbeing* in a whole-school approach. This has involved changes in the ethos of the school environment, which has also influenced classroom-based teaching approaches.

From an educational perspective, the relevance of mental health is not necessarily the absence of mental illness but includes attributes such as agency, autonomy, and optimism (Weare, 2000). These positive mental health aspects of emotional wellbeing and social functioning are all perceived relevant to improve young people's academic attainment (Murray et al., 2007; Durlak, Weissberg & Dynnicki, 2011) which is an agenda favoured by many educationalists, parents, and politicians.

The philosophical role of schools to promote young people's mental wellbeing has been well established since the Plowden Report (1967) emphasised the need to encourage young people to engage in 'individual discovery'. This role is contrary to the frequent criticism against schools who are 'teaching to the test', and harming young people's mental health (Kruger et al., 2007). This has supported the need for schools to take a more pro-active role in looking after the young person's mental wellbeing to improve academic attainment (Murray et al., 2007; Durlek, Weissberg & Dynnick, 2011; Bradlru & Green, 2013). From this perspective a focus on psychosis literacy would have virtually no educational appeal, be perceived as possibly irrelevant and should remain within the realms of psychiatry.

In the UK, the ethos within schools has promoted the role of education in protecting the vulnerability of young people. This has taken the form of anti-bullying policies, change in discipline policies and change in the teacher's pastoral role to support young people. These approaches have focused on changing young people's behaviour to create a sensitive, positive, and caring school environment.

One developmental change in the ethos of schools occurred in 2007/8 when the initiative Social Emotional Aspects of Learning (SEAL) was rolled out to schools as a framework to create 'a comprehensive, whole-school approach to promoting the social and emotional skills that underpin effective learning, positive behaviour, regular attendance, staff effectiveness and the emotional health and well-being of all who learn and work in schools' (DCSF, 2007, p.4). A National Strategies' waves intervention model involved SEAL within a 'whole-school universal' approach, viewing the school as a community (Banerjee, 2010; DfES, 2005).

SEAL was based on Goleman's (1995) model of emotional intelligence to learn the skills of self-awareness, self-regulation (managing feelings), motivation, empathy, and social skills. Possession of such *intelligence,* however, does not necessarily equate to an improvement in young people's ability to enter into loving, co-operative and community relationships. Hence Steiner (1997) differentiates emotional *intelligence* from emotional *literacy* through the achievement emotional literacy has in promoting loving, co-operative work within the community. There was an assumption that young people were deficient of emotional intelligence (EQ) resulting in emotional illiteracy. Mental *illness* remained clearly irrelevant when considering the general wellbeing of young people and only relevant in waves 2 and 3 of the targeted Social Emotional Wellbeing (SEW) skills to young people 'thought to be at risk' (DfES, 2005).

It is arguable however that the SEAL framework did provide the potential to encourage young people to relate to others with mental illness conditions and encourage general awareness against emotions of prejudice and stigma. SEAL emphasised the need for young people to have the ability to respond to the emotions of others, in ways that are helpful to ourselves and others (Weare, 2003). It remained though unclear from national evaluations of SEAL the extent and manner to which schools used SEAL to focus on mental illness directly or not. Findings concluded that SEAL remained fragmented, variable, and sometimes superficial (a ticking-the-box exercise) (Humphrey, Lendrum & Wigelsworth, 2010). Thus, creating great difficulty in evaluating the different SEAL approaches schools have used (Banerjee, Weare & Farr, 2014). The opportunity to focus on mental illness within the SEAL initiative did not occur.

Participation in the National Healthy Schools Programme (NHSP) is another example driven by concerns about young people's food choices and lack of physical activity. Currently, schools can still retain the 'healthy school' status, but the programme no longer benefits from governmental targets or funding (Bonell et al., 2014), and remains entirely non-statutory. The programme also neglected any consideration of the relevance of mental illness (DfES, 2004), including any ethos change of attitude towards the need to discuss mental illness. Parity is missing for mental health in contrast with physical health, and there does not seem to be any emphasis or incentive for the NHSP to challenge this lack of parity. The schools' focus on young people's *emotional health and wellbeing* needs have remained directed to improve young people's social awareness, participation and understanding of sex and relationship issues. There is a neglect in obtaining young people's views if this is a correct portrayal of their health needs.

One ethos change that has directly approached the topic of mental illness has been the opportunity for schools to engage in the 'time to change' campaign. The campaign continues to combat the stigma of mental illness and act as a strategy to enable young people to seek and receive support from counselling services (DH, 2016). The 'time to change' campaign recognises the need to talk about mental illness and not shy away from the taboo nature of the topic. Unfortunately, such attempts may inadvertently prevent the extent to which young people can openly discuss the topic of mental illness, as the young people may feel judged as already being stigmatised and not feel able to engage in full open discussion.

Educational policy has also notably changed direction since 2010 due to a change in government from New Labour to a Coalition government under the Conservatives and Liberal Democrats. Initiatives such as SEAL and NHSP, which were having an influence within the classroom, took a significant step back within schools as focus turned to maximise academic attainment. Ofsted frameworks became focused on assessing academic subjects rather than pastoral responsibilities (Ofsted, 2012). Recently, there has been another change in political direction as Ofsted's common inspection framework (2015) now identifies the importance of assessing the school's role in developing young people's personal development, behaviour and welfare, specifically how to keep themselves healthy, both emotionally and physically. This involved an increase in opportunity for schools to focus on specific class-based taught sessions within the National Curriculum to address young people's mental wellbeing needs.

2.3.3 Teaching about 'mental wellbeing': class-based specific curriculum

Class-based curriculum opportunities have varied in nature but have aimed to improve young people's individual cognitive (thinking) or affective (feeling) attributes, specific behaviours, or skills, as well as explicitly improving mental health or preventing mental illnesses (Wells, Barlow & Stewart-Brown, 2003). The main aim is to build young people's level of resilience and prevent neglect of mental wellbeing to prevent mental illness from occurring. There has remained a lack of aim within these class-based programmes to address the general MHL needs of young people.

In 1997 the Crick Report recommended that Citizenship should form part of the National Curriculum to ensure young people learn skills how to become active and responsible citizens. Personal, Social, Health and Economy Education (PSHE) and Life Skills provision within schools have similarly been concerned with the wellbeing of the young person, motivated by the fear that young people were becoming radicalised, anti-social or mentally ill. Nevertheless, these classroom-based initiatives have the ability and potential to increase awareness of mental illnesses. The problem lies in the fact that there is little evaluation about what schools should cover, and how, within this topic.

Section 2.5 of the National Curriculum states that all state schools should make provision for PSHE and the DH (2013) guidance for PSHE states that the subject is an important and necessary part of all pupils' education, but schools can currently still opt out of delivering such a curriculum, and academies, free schools and independent schools are not bound by the National Curriculum. PSHE guidance (DH, 2013) has no specification on teaching mental wellbeing or illness in PSHE. The focus remained on building upon 'statutory guidance on drug education, financial education, sex and relationship education (SRE) and the importance of physical activity and diet for a healthy lifestyle'. The belief is that these topic areas are more relevant to young people's needs.

The recent change in focus within current political legislation and policy now has specific reference related to the school's role to promote young people's emotional wellbeing and resilience (House of Commons Education and Health Committees, 2017). More detailed guidance what this should include has not yet been specified in preparation for PSHE to become statutory from September 2019 through an amendment to the Children and Social Work Bill (2017). Nevertheless, the DH & DfE (2017) have made it a manifesto commitment that every child will learn about mental wellbeing. The Government is currently in an engagement process to decide how mental health and wellbeing is taught through PSHE. The hope is that future statutory guidance on PSHE can improve the level of uncertainty and variation currently experienced across schools.

The PSHE association responded to this change in March 2015 by producing specific guidance for teachers on how to teach about mental health and emotional wellbeing. The current PSHE association (2015) guidance still generally avoids consideration of specific mental illnesses but aims to improve young people's healthy coping strategies and increase understanding of their own emotions as well as those of other people to increase support and seek help. These sets of skills correspond to the previously defined emotional literacy approach, with the exception that specific teaching has stipulated the exploration of specific emotional wellbeing issues such as bullying, fear of failure, body image, the online environment, sexual pressures, and employment prospects.

The PSHE association (2015) did not totally disregard the need to consider specific mental *illnesses* but perceived that this was only right for older young people at Key Stage 4. This decision shows the feeling that mental *illness* is a taboo issue that needs maturity and is not relevant for younger people’s wellbeing needs (under 15 years old). In fact, such a decision may reinforce the level of taboo towards this topic, and does not acknowledge the relevance of the topic for younger people.

The decision for the PSHE association (2015) to stipulate specific types of disorders which young people should be taught about also needs to be questioned further. Serious mental illness topics were avoided in favour of more suitable teaching strategies to manage stress, anxiety, depression, self-harm, and suicide. This shows that the motives involved in PSHE association (2015) guidelines reflect the current Government concerns about specific mental health problems highlighted as particularly problematic for young people (DH & DfE, 2017).

Fears also exist within the PSHE association (2015) guidelines that young people could enter discussions about inappropriate behaviours or could invite stigmatised comments. Specific stipulation outlined what was inappropriate when discussing mental illness: methods or instructions of self-harming or eating disorders and the use of emotive language. These concerns are justifiable, but also contradictory to one of the guidance’s aims to create an environment where young people can talk openly about mental health issues. There exists a danger that adult professionals are deciding what is and is not appropriate to the detriment of neglecting important discussion points surrounding mental illness for young people. The perceived dangers that are held against the use of such ‘therapeutic education’ will now be outlined.

2.3.4 ‘The Dangerous Rise of Therapeutic Education’

In response to the overwhelming tide of changes implemented since 1997 (from New Labour’s new educational policy changes), Fuedi (2004) and Ecclestone & Hayes (2009a; 2009b) have taken an alternative critical stance on such changes. This academic debate has raised concerns how educational initiatives concerned with young people’s emotional development may promote a diminished image of young people. Young people became inappropriately problematised and medicalised within the school environment.

Furedi (2004) put forward the idea of the ‘diminished self’, criticising public and political fear and preoccupation with risk, danger and vulnerability caused by being emotionally *deficient*. Labels of ‘vulnerable learners’, ‘at risk learners’, ‘fragile identities’, ‘the hard to reach’ and ‘low self-esteem’ have become prevalent and accepted within schools. Ecclestone & Hayes (2009a; 2009b) criticises such notions as creating emotional fragility among young people, it is anti-educational in that it lowers educational and social aspirations and normalises young people as flawed and vulnerable. Thus, it is seen as socially engineering young people to become dependent on emotional support.

The school environment has been criticised for entering the realms of everyday preoccupation with emotional vulnerability, attacking liberal humanistic education. Humanistic and humanitarian education (therapeutic education) has disapprovingly, according to critics, embedded the idea that emotional wellbeing, emotional literacy and emotional competency are some of the most important outcomes of the educational system. Ecclestone & Hayes (2009a; 2009b) has felt that such an unhealthy obsession in exploring emotions and the self within education has led to the erosion of subject disciplines within the curriculum.

It is true that therapeutic education originates from an unhealthy level of anxiety about young people’s vulnerability, but these criticisms remain directed from a political and professional perspective about what young people’s educational needs should be. I am not proposing that an exploration of young people’s wellbeing is wrong or right, but it should not be in the hands of a few politicians or educationalists to decide what is dangerous or important for young people.

In fact, comments made by Ecclestone & Hayes (2009a; 2009b) and Furedi (2004) show their concern about young people being deficient in emotional control to be engaged in such therapeutic initiatives. Hence, this suggests that young people are vulnerable and need protecting from this change in educational agenda. There has been no consideration, however, whether young people feel that the so-called therapeutic turn in education does make them more vulnerable. Before making judgements of this kind surely it is important to interpret this experience from a young person’s perspective.

Weare (2004), on the other hand, illustrates the importance of ‘developing the emotionally-literate school’, particularly via developing positive self-concept, self-protection, making relationships, resisting pressure, stress management and negotiation. In response to the argument put forward by Ecclestone & Hayes (2009), it is instead suggested that the emotional literate skills that young people gain empower young people and prevent vulnerability. The purpose of psychosis literacy could be beneficial in providing young people with a forum to value young people’s own emotional wellbeing and highlight the importance of combatting stigma related to mental illness to reduce bullying and stereotyping.

There is finally also one word of caution about the ‘dangerous rise of therapeutic education’, in that it is dependent on if the motive of the intervention was therapeutic. For example, increasing awareness of ‘other’ people’s mental illnesses removes the personal element of the initiative. These types of initiatives require further exploration.

2.3.5 MHL interventions

In contrast with the educational initiatives that have focused on the general mental wellbeing needs of all young people, attention will now refocus on general MHL initiatives. These initiatives have originated from health community professionals rather than educationalists and are driven by health promotion.

One of the dominant MHL approaches advocated within the school environment in the UK has been the advance in MHFA. The DH & DE (2017) has recently supported the need for MHFA to help identify, and promote awareness of, mental health. The aim of increasing awareness has been based on the motive of minimising risk. The Youth MHFA training programme, for example, provides teachers and frontline professionals working with young people the skills and confidence to spot common signs and triggers of mental health issues, as well as the knowledge and confidence to help (DH & DE, 2017).

The use of MHFA is therefore still preoccupied with the personal meaning that mental health has on the young person and has placed increased responsibility on teachers to have better literacy to help identify and increase support for their students. In this example, there is a significant overlap illustrated within the motive of providing MHL to personally prevent mental health problems for themselves as well as others.

The main aim of MHL interventions within this literature review has been to decrease mental health stigma. Dialogue about mental illness remained concerned about ‘other’ people and does not intend to provide young people with the emotional literacy skills focused upon in whole-school approaches. The interventions have instead remained preoccupied in conducting quantitative survey-based measurements, based on aiming to improve levels of stigma (Chan, Mak & Law, 2009; Essler, Arthur & Stickley, 2006; Esters, 1998; Lauria-Horner, Kutcher & Brooks, 2004; Meise, Sulzenbacher, Kemmler, et al., 2000; Naylor, Cowie, Walters, et al., 2009; Ng & Chan, 2002; Pejović-Milovancević, Lecić-Tosevski, Tenjović, et al., 2009; Pinfold, Toulmin, Thornicroft, et al, 2003; Pitre, Stewart, Adams, et al., 2007; Rickwood, Cavanagh, Curtise, et al., 2004; Schulze, Richter-Weling, Matschinger, et al, 2003; Shah, 2004; Spagnolo, Murphy & Librera, 2008; Stuart, 2006; Watson, Otey, Westbrook, et al., 2004).

The lack of qualitative consideration about young people’s experiences or views of involvement in such initiatives is concerning. Outcomes assessed have only been based on considering how young people’s level of stigma has changed according to the literacy intervention put in place. This approach only increases the emphasis that mental illness is someone else’s problem and does not relate to the young person’s own wellbeing needs. Qualitative consideration about young people’s meaning and understanding of mental illness would ascertain if MHL interventions have inappropriately blocked out relevant wellbeing concerns or have even misinterpreted young people’s stigma.

The problem within such an anti-stigma direction is that it has the effect of assuming and interpreting young people as stigmatising. It creates, sustains, and acknowledges that high-levels of stigma exist among young people. The underlining assumption in these initiatives is that young people are stigmatising based on the belief that young people have mental health illiteracy. There is no consideration or appreciation of young people's existing knowledge and understanding of mental illness. The aims of the interventions stay focused on providing young people with literacy about mental illness and then evaluate the impact such literacy has on changes in young people's knowledge, attitude, or behavioural intention (assessed by social distance measures) towards individuals with mental illness. Interpretation of these results is under the belief that improved literacy corresponds with reduced stigma, and that there are clear truths and facts about mental health that can improve young people's literacy. No appreciation is given to the contested professional discourse surrounding mental health and social construction surrounding the interpretation of mental illness (see Chapter 3 for discussion). Young people's literacy about mental illness is formed continuously within a social context from their friends, family, media, and sociocultural factors.

The nature of these survey-based evaluations has resulted in interventions tending to be one-off and conducted over a brief period: lasting from one hour (i.e. Spagnolo et al. 2008) to longer fifty-minute lessons over a period of six weeks (Naylor et al. 2009) conducted by external health professionals with a general lack of synthesis between health and educational professionals. Determining the effectiveness of these interventions arguable is significantly flawed when evaluating changes over such a brief period in a sterile experimental environment.

The interpretation of changes in young people's positive attitude because of these interventions requires further critical consideration. The effect of reporting attitude change to professional adults within an educational setting needs consideration. Participants will want to display more socially desirable attitudes when involved in interventions that directly convey the message that stigmatisation is undesirable (Haghighat, 2001). Using pre-post research design methods involving attitude measurement instruments invites young people to be more likely to give right answers regardless of their opinions. Approaches to reduce stigma potentially puts forward a view that simplifies the stigma that surrounds mental illness. This highlights the need to take young people's views seriously outside of the influence of interventions implemented on them, giving them the confidence to discuss issues that are relevant to them and not necessarily conforming to responses expected. Young people need to believe that interventions are suiting their needs and having a *real* rather than *perceived* effect on them.

The panacea of improving young people's literacy is acknowledged too effortlessly without questioning the nature of these literacy initiatives. There is a significant lack of detail about the format or content of the interventions themselves documented within the research. From a pedagogy perspective, this information would be essential to evaluate what worked well with the young people, qualitatively exploring young people's understanding of mental health to inform the development of educational material. Unfortunately, an educational perspective on the provision of this information has not been commonplace, making it at times difficult to evaluate the nature of the initiatives conducted.

The opportunity for young people to decide what type, content or method of intervention is significantly missing. Most interventions stated that external experts within the arena of mental health were used to deliver them within schools. Expert decision-making skills decided what was the *correct* and most *relevant* literacy for the young person, as illustrated in the reliance of external designed material for schoolteachers to deliver (Schachter et al., 2008). No opportunity to consult with young people (or even teachers) is evident in this process. Nevertheless, the next section of this literature review will try to evaluate some of the main methods that have been utilised within existing initiatives.

2.3.6 What literacy methods have been evaluated in relation to improving MHL?

To evaluate the success and value of existing MHL approaches, this section of my literature review will explore the variety of different pedological methods in MHL. The lack of evaluation of these methods, and lack of rationale of choices made for these approaches highlight the need for more research within this area.

2.3.6.1 Lecture/Presentation method

In Sakellari et al. (2014), Economou et al. (2011) and Economou et al. (2014), a two-hour lecture and discussion dismissed myths about mental health. Evidence-based information defined and described mental health and the experience of mental health and mental health prevention. The content of this information involved the biological, psychological, and social causes of specific mental illnesses, the lived experiences of mental illness, and different forms of treatment of these illnesses (Sakellari et al., 2014). Similarly, an interactive 35-minute PowerPoint presentation was the main method used in Saporito et al. (2011) to provide basic information of mental illness in general and then more specific aspects of mental illness regarding common diagnosis and treatment.

These lectures/presentations did utilise specialists to deliver the information, as a health professional (the researcher) conducted the intervention in Sakellari et al. (2014) and two psychologists were used to deliver the intervention in Economou et al. (2014) and a psychiatrist and psychologist was used in Economou et al. (2011). The only exception was in Saporito et al. (2011) where there was no information who delivered the PowerPoint presentation. The use of specialists does give the impression that the young people were treated as passive recipients of their learning. No evaluation on the young people’s feelings about the use of lectures/presentations or the involvement of specialist teachers, makes it difficult to make judgments about their suitability from a young people’s perspective.

2.3.6.2 Role-play, creative artwork, and video

In Economou et al. (2014) young people also engaged in role-play activities and certain vignettes to explore how they would feel if they were stigmatised. Poster painting and artwork enabled young people to express the experiences of severe mental illness. Economou et al. (2011) similarly utilised role-play to discuss the experience of stigma and engage in a collective drawing activity. Hence while the researchers felt that lectures/presentations were important, they acknowledged that these types of teaching methods could not enable young people to empathise with the experience of having a severe mental illness. This type of literacy was not fact-based, but involved teaching methods to explore their emotional intelligence.

Economou et al. (2011; 2014) did not justify their reasons why these methods were chosen as more suitable when discussing specific topics related to severe mental illness and stigma. This may suggest that adults are reluctant to engage in direct discussion about severe mental illness because of the fear that young people may discuss inappropriate/stigmatised views or may lead to undue worry and anxiety.

Saporito et al. (2011) similarly acknowledged the need for more interactive methods to encourage young people to dispel their own misconceptions about mental health. The imagery of celebrities struggling with mental illness was one method used. The other method was showing a video with a 19-year-old male diagnosed with depression and ADHD. These methods aimed to enable young people to relate to the difficulties involved in a person’s life and their ability to live a normal life. Once again, no consultation with young people provided an exploration of the reasons why the use of such visual stimulus and engagement may be beneficial.

In Naylor et al. (2009) six fifty-minute lessons on mental health issues were evaluated once a week, utilising age-appropriate Royal College of Psychiatrists booklets and factsheets, video films, discussions, role-playing and internet searching. Pinfold et al. (2003) similarly conducted two one-hour sessions involving mental health awareness workshops using short videos to consider young people’s understanding of mental health and mental illness. These were supported by group exercises including information leaflets aimed at challenging stereotypical labels. The aims of these interventions were to utilise a variety of different approaches to cater to different learning styles and promote engagement.

In Chan et al. (2009) the researchers set out specifically to evaluate the effectiveness of video media to reduce stigma directed towards schizophrenia. This was evaluated by comparing three types of interventions. This first involved only a 30-minute demythologizing lecture followed by a 5-minute question and answer session, which involved an element of role-playing in treating a person with schizophrenia respectfully. The second intervention involved this form of education followed by a contact video of 15 minutes titled ‘The Same or Not the Same’. The third intervention implemented the opposite sequence of the video and then the education. The video involved four people (2 female and 2 males) diagnosed with schizophrenia aged 18-24 talking about their experience of recovery, independence, employment, quality of life, the symptoms of the illness, stigma and overcoming difficulties. The aim of the video was to illustrate the similarity of needs, interests, and lifestyle of these young people with the targeted audience of secondary school children aged 13-18.

The results of Chan et al.’s (2009) study were that the education-video sequence showed less stigmatised attitudes, shorter social distancing scores and a higher level of knowledge about schizophrenia than just the educational intervention or the video-education sequence. There was no difference in stigmatised attitudes between the video-education sequence intervention compared with the education intervention. Chan et al. (2009) concluded that the method of a lecture on schizophrenia allowed young people to have sufficient information and background knowledge to allow deeper processing of the video contact method utilised.

The concluding results that Chan et al. (2009) have portrayed are based on measures of stigmatizing attitudes (Public Stigma Scale), social distance (Social Distance Scale), and knowledge about schizophrenia (Knowledge Test) at pre-test, post-test, and 1-month follow-up of 255 students from three secondary schools in Hong Kong. The interpretation of results is based on set criterions used to determine the extent of young people’s stigma. The preoccupation of measuring stigma neglects consideration of young people’s understanding about psychosis and exploring the influence of the literacy approaches used.

2.3.6.3 Direct contact with a service user with a mental illness

In contrast with the educational methods described above, the use of direct contact with someone with psychosis has primarily aimed at reducing levels of social distancing and exploring the lived experience of psychosis. Less focus has been on informing young people about the clinical facts about psychosis. The evaluation of such interventions has been difficult, as the contact that young people will have with these individuals will change according to the dialogue that the young people choose to engage in as well as the different individuals used in the intervention.

During Schulze et al.’s (2003) and Conrad et al.’s (2009) studies, the intervention called ‘Crazy? So What!’ did not utilise any formal lecture structure and no professional or specialist was involved in delivering the session. The focus of delivery was based on young people meeting another young person with a mental illness. The young person used in these interventions were perceived as the experts of their own lived experience of mental health.

In Schulze et al.'s (2003) study contact made was with someone who had specifically experienced schizophrenia, although their age was not specified. Whereas in Conrad et al.'s (2009) project, experts were aged 25-30, with an experience of drugs and psychosis, depression and bipolar and were from a military background. The researchers do not comment on how age and background of these service users may influence and alter their understanding of the lived experience of mental illness. Similarly, the 'In Our Own Voice' intervention, evaluated in Pinto-Foltz et al. (2011), included two trained young adults (over 18) who had recovered from a mental illness who discussed their first-hand experiences of mental illness for 60 minutes. The effect of the service user's age (a young adult over 18) or the influence of having training, was questioned by Pinto-Foltz et al. (2011). These are questions that require further exploration from a young person's perspective.

In Pinto-Foltz et al. (2011) there was more detailed information provided by the researchers about what the service users would discuss. The reason for this was because the service users had training with a stipulated agenda to discuss their first experiences of the illness, 'the Dark Days', leading to their experiences of acceptance, treatment, coping and recovery. Rickwood et al. (2012) also delivered a mental illness education programme by trained service users to supply a standardised presentation to dismiss myths about mental illness and provide information about mental health services and resources available. The detailed content of these interventions is useful as a means of evaluating the nature of these programmes, but lends itself to question why the interventions have not allowed the flexibility and informal approach taken in programmes such as 'Crazy? So What!'. It may be due to professional anxiety that the interventions are directed to supply a positive anti-stigma attitude towards psychosis.

In Chisholm et al.'s (2012) study, a pilot trial of a one-day intervention in a school in Birmingham aimed to decrease the stigma of mental illness, improve MHL and improve the young people’s mental health. Young people with mental illnesses in this intervention worked with the young people as one of the teaching assistants, as well as NHS Mental Health specialist staff, in a 10 to 20-minute presentation and interactive discussion about living with a mental illness.

Interestingly in Pinfold et al.’s (2009) study, the young people involved in the intervention demanded the involvement of a service-user to discuss their experiences of mental illness. Pinfold et al. (2009) responded by training and using co-facilitators who had individual experiences of mental illness to sensitively share their experiences with the young people through a short discussion and question-and-answer session. This proves that, initially, professionals did not actually view involving service users to improve young people’s literacy surrounding the lived experience of mental illness as suitable or effective.

On a positive note, Schulze et al. (2003) did aim to enable young people to explore their personal emotional wellbeing and relate to the experiences of the young person with schizophrenia; considering the nature of the illness, available treatments, and the experience of stigma. The aim of this intervention was to engage the young people in interactive group discussion to give a chance to relate to the lived experience of psychosis. The extent that young people can relate to severe mental illnesses such as psychosis requires further exploration.

2.3.6.4 School Mental Health Programme

In contrast with the other separate individual interventions mentioned, Rahman et al. (1998) evaluated a School Mental Health Programme. This programme was exceptional in terms of implemented activities within the existing school curriculum, conducted within speech/essay writing, poster competitions, short plays and short lectures, all delivered over a longer 4-month period. The primary specialists to implement this programme did not involve any mental health professionals or service users but relied solely on the school teachers. A team of doctors, psychologists and social workers worked instead prior to its delivery with teachers to assess their existing knowledge on topics of mental health, and then implemented a short training course on common mental health to prepare the teachers to deliver this School Mental Health Programme.

A plausible reason for Rahman et al.’s (1998) different approach is because the School Mental Health Programme was conducted in a rural community of Pakistan. The cultural, economic, and environmental influences would have determined the approach taken in this intervention. It is unlikely UK school teachers would feel prepared and have the necessary ability needed to conduct the programme, as this surely would be a fundamental factor determining the effectiveness of this intervention.

A variety of different pedagogical approaches has been utilised in MHL initiatives. There is clearly a need to obtain young people’s views and opinions about these approaches in this study. Next, an appraisal about the content of these literacy approaches will be evaluated, specifically surrounding the topic of psychosis.

2.3.7 Is psychosis addressed within MHL interventions?

As previously discussed in sections 1.3, 2.3.3 and 2.3.4 there has been little focus on psychosis or schizophrenia within the school environment due to the fear that this would create more stigma or the rationale that this topic was irrelevant for young people (PSHE Guidance, 2015). However, this section will take a more detailed focus on how MHL interventions did approach the topic of psychosis, and the impact this has had on the intervention.

The justification in MHL interventions was to focus on more common mental health issues relevant and right for young people (Naylor et al., 2009; Howard et al., 2008; Saporito et al., 2011). In Naylor et al.’s (2009) study this included the decision to include the topic areas of stress, depression, suicide/self-harm, eating disorders, bullying and intellectual disability. In fact, within the MHL literature reviewed, the terms ‘mental health’ or ‘mental illness’ lacked definition of the types of illnesses explored (Saporito et al., 2011; Economou et al., 2014; Chisholm et al., 2012; Pinto-Foltz et al., 2011; Rickwood et al., 2012). There was more importance attached to supply general basic information about mental illness in terms of illustrating common diagnosis and treatment (Saporito et al., 2011).

There was also greater justification within MHL interventions to focus on the mental health wellbeing of young people to help the young people to relate to mental illness more readily. For example, Conrad et al. (2009) defined mental health issues as the young people's own experiences of 'good or bad times in their lives'; understanding that if young people are able to relate to mental illness more readily, the outcome is likely to reduce stigma from developing. Esters et al. (1998) also recognised the advantage of utilising the term 'emotional problem' to assess young people's help-seeking responses. The focus of O'Kearney et al.'s (2009) and O'Kearney's (2006) online training programmes aimed to help young people to learn cognitive behaviour therapy skills to prevent and cope with depression. These engaged in skill exercises involving relaxation, problem-solving, assertiveness, self-esteem, and coping with relationships. The aim was to avoid the clinical diagnostic meaning of depression and relate depression casually to young people's feelings and thoughts.

This approach nevertheless has not allowed young people the chance to discuss serious mental illnesses in relation to their own wellbeing. Instead, MHL initiatives have indirectly increased the taboo nature of discussing illnesses, such as psychosis, through avoidance. There has been a lack of opportunity for initiatives to explore psychosis in relation to young people's wellbeing even though, as previously mentioned, the prodromal symptoms of psychosis are all features of common mental health experiences.

There are also problems associated with the decision to interpret the experiences of stigma and lived experiences as the same for different mental illnesses (Rickwood et al., 2012, Pinto-Foltz et al., 2011). Rickwood et al. (2012) addressed the stigma and myths of mental illness in the Mental Illness Education programme in the Australian Capital Territory as a collective experience without identification of specific stigma attached to specific illnesses. This approach creates inappropriate assumptions towards how mental health is perceived, as illustrated when severe mental illnesses were explored in Economou et al. (2014) without a definition what types of illnesses these included. Assumptions should not classify what illnesses are more severe, as this could create more stigma. The intervention 'In Our Own Voice' also made no distinction how individual mental health experiences would be vastly different when involving people who have personally experienced mental illness (Pinto-Foltz et al., 2011).

Interventions that did specifically consider schizophrenia or psychosis were all focused on reducing the stigma attached to this illness. There was an assumption that young people stigmatise this condition more than other illnesses. For example, Economou et al. (2011) engaged young people by role-playing the experience of stigma of schizophrenia**;** Chan et al. (2009) dismissed 13 myths about schizophrenia and utilised the video 'The Same or Not the Same' to demonstrate the ability to recover from schizophrenia; and elsewhere contact with a young person with the diagnosis of schizophrenia was utilised to break 'social distancing' (Schulze et al., 2003; Conrad et al., 2009). The dialogue surrounding psychosis is based on an anti-stigma framework that prevents the ability and freedom to openly question and discuss this topic.

Rahman et al. (1998) did use the term 'psychosis' rather than the diagnosis of schizophrenia. However, no explanation or meaning is attributed by Rahman et al. (1998) to this term. This highlights the influence that terminology can have on literacy interventions, as schizophrenia became generally contrasted as more severe than other common mental health conditions (Conrad et al., 2009; Sakellari et al., 2014; Pinfold et al, 2003; Rickwood et al., 2012; Pietre et al., 2007). The lack of rationale for their choice of illnesses deepens the mistrust and scepticism of the researcher's preconceived ideas about choosing to contrast depression and psychosis. Sakellari et al. (2014) focused on bipolar, depression and schizophrenia; Pinfold et al. (2003) focused on depression and schizophrenia; Economou et al. (2011) created synonymous meanings between 'mental illness' and 'schizophrenia'; and Rickwood et al. (2012) measured the achievements of the MIE-ACT programme according to young people's responses to 2 vignettes involving someone with schizophrenia and depression. The comparison between these mental illnesses can indirectly prevent young people from understanding psychosis as a wellbeing concept.

In Pitre et al.'s (2007) study the use of puppet characters for younger children aged between 8 and 11 opted not to have a character experiencing schizophrenia compared with the other two puppets with dementia and depression/anxiety (Pitre et al., 2007). The rationale for this decision is based on the premise that presenting symptoms of schizophrenia could potentially increase stigma related to the illness (Penn et al., 1994). Instead, the puppet factually described the symptoms of schizophrenia his mother experienced and his experience of bullying by others about his mother being ‘cuckoo’, while a friend comforts him and asks him questions about the illness. This rationale supports professional motives to make psychosis a condition that affects adults and other people in order not to scare young people, showing reluctance to consider psychosis when implementing anti-stigma interventions.

The persistent professional anti-stigma agenda set when considering psychosis or schizophrenia with young people may also ironically increase the perceived stigma and severity of psychosis. The focus on stigma or lack of knowledge of psychosis reinforces the notion that young people will hold these values, and does not start to appreciate young people’s own understanding and knowledge about psychosis. In Chan et al.’s (2009) study, the 15-minute video entitled ‘The Same or Not the Same’ portrayed four individuals diagnosed with schizophrenia aged 18-24 who had regained their independence, gained employment and had overcome symptoms and stigma of the illness. These individuals had similar needs, interests, and lifestyles to the young audience. Similarly, Schulze et al.’s (2003) study involved meeting a young person with schizophrenia. The rationale behind such interventions was to reduce stigma by increasing the relevance of the experience of schizophrenia to the young person.

MHL interventions have largely advocated a biogenetic explanation of mental illness, emphasising messages such as ‘mental illness is an illness like any other’. This message has underlined the reason for using puppets (Pitre et al., 2007), creating theatre productions (Essler, Arthur & Stickley, 2006) and meeting people with lived experience of mental illness to destigmatise mental illness (Couture & Penn, 2006; Couture & Penn, 2003). Indirect contact (Schulze et al., 2003; Spagnolo, Murphy & Librera, 2008) or video-based contact (Chan, Mak & Law, 2009; Stuart, 2006) attempt to destigmatise the experiences of mental illness.

Young people’s literacy about schizophrenia was assessed in Stuart’s (2006: p.650) study by asking true or false questions to twelve ‘factual’ statements.

Examples included “schizophrenia is caused by stress” (correct answer: false); “people with schizophrenia need medication” (correct answer: true); and “schizophrenia is a brain disease” (correct answer: true). The factual construction of these statements does not allow young people to question or challenge the perceived solidity of answers provided. In fact, there is no conclusive evidence what causes schizophrenia (Bentall, 2003), some people with schizophrenia argue medication has done them more harm than good (Moncrieff, 2004), and there remains considerable disagreement as to whether or not schizophrenia and other mental illness can be regarded as a disease (Szasz, 1960). A biogenetic approach taken in these initiatives deny alternative explanations.

Overall this literature review has found a significant lack of focus applied to psychosis when implementing mental health promotional interventions in schools. Instead, interventions have tended to consider mental health generally or have compared specific mental illnesses against the severity of schizophrenia. No attempts have explored how young people have understood the meaning attached to the lived experience of psychosis. Critics of the MHL approach have shown the importance of focusing on the social constructional understanding of an individual’s literacy.

2.3.8 Critics of the MHL approach

The MHL approach in schools could be viewed as insufficient in terms of not considering young people’s belief structures in understanding or interpreting mental illness. The approach remains focused on its aim to enable young people to diagnostically recognise mental illness.

Critics have taken this viewpoint when challenging the lack of understanding literacy interventions have taken towards service user’s experiences of mental illness. Gattuso, Fullagar and Young (2005) described MHL as an unsophisticated one-way model of communication in which individuals are supposed to ‘absorb’ correct health messages. People who refuse to take up the expert view of depression as illness were interpreted as non-compliant, ignorant, or, in the dominant discourse, illiterate. This research considered women’s beliefs about depression, but equally the concept of MHL viewing young people as illiterate requires similar scrutiny. Young people should no longer be deemed as literate according to their ‘degree of belief in biogenetic explanations and the ability or willingness to apply diagnoses’ (Read et al., 2006, p.305).

The problem that has existed with the critics of mental literacy has been the silence that has fallen on its application towards views of general young people. This is because the critics have been able to challenge the notion of expert professional opinion considering the service user movement, who view themselves as the actual experts of their own experiences. Currently, for example, Youth Speak has promoted the voice of young people as service users to understand their needs in relation to mental health research, tackling the stigma of mental health and influencing the development of young people’s mental health services (http://www.youthspeakmh.com). Young people in this project have become valued as experts because of their mental health, while other young people are the problem of *their* stigma. Critics have placed the superiority of service user’s experiences in the place of a biogenetic agenda, but in doing so have devalued non-service user’s views and opinions.

MHL critics have also been very sceptical, as I have, about the idea of literacy in terms of knowledge where the truth lies within the field of psychiatry. The implication is that experts know what type of help should be provided and what is the most appropriate help-seeking approach, presenting understandings of mental illness from a professional outlook. This dismisses the lived experience of mental illness and ignores the lack of concord and dispute in psychiatry itself (see section 3.1).

2.3.9 Summary

Drawing together the different approaches taken in schools how mental health wellbeing/illness has been taught, and the critics of these approaches, it has become apparent that a new way of approaching this topic is needed without a professional adult agenda tinting the direction of the approach made.

This is not to say that professionals are incorrect in how they have approached this topic, as all approaches considered in this literature review have had the best interests of the young person at the heart of its aims. What I am saying is that a separate way of looking at this issue from a young person's perspective could challenge taken-for-granted views about young people's needs. The result could open a new outlook on how literacy interventions can address young people's needs in a more appropriate and effective manner. My final section of this literature review will focus more specifically on existing research literature that has tried to shape MHL interventions by considering young people's views and opinions.

2.4 Have young people's views and opinions influenced the implementation of school-based MHL?

It is expected from my previous review of the literature, that there has been a neglect in considering young people's views and opinions about their MHL needs in school. Hence, this is an area of research that requires further exploration, as results during focus group discussions and individual interviews involving 120 Scottish young people felt that their unique mental health problems were trivialised or devalued from an adult perspective (Armstrong, Hill & Secker, 2000).

Specific focus has continued to direct literacy interventions to improve young person's emotional wellbeing (to improve educational attainment) and to reduce young people's stigma (to encourage access to mental health services). These approaches aim to improve education and mental health services but have neglected to ask whether these aims are relevant or important for young people. This provides further rationale to improve the level of young people's involvement in research to obtain a clearer exploration of young people's views and opinions about their MHL needs without adult involvement.

Despite the relative dearth of qualitative research literature in this area of research, there have been attempts to explore young people's views and opinions regarding MHL. One of these research studies was Armstrong, Hill & Secker (2000) where focus group discussions and individual interviews involving 120 Scottish young people showed that young people did hold strong views of what they wanted and needed about issues which affected their positive mental health. The young people highlighted the importance of trust and having the chance to talk about their mental health. It is noteworthy however that Armstrong, Hill &

Secker (2000) chose to focus specifically on positive mental health, and specifically avoided discussion related to mental health illness. The consequence of this decision was that young people’s dialogue became embroiled within a mental health promotion framework and did not allow a flexible dialogue for young people to discuss mental health within their terms of reference.

Kidger et al. (2009) held similar priorities when conducting focus group sessions with 154 young people aged 12-14 in English secondary schools. The focus groups centred on considering the lack of emotional health wellbeing provision within the school curriculum and the importance attached by the young people to improve such provision. The results from Kidger et al. (2009) were that young people felt that topics such as sex and drugs were prioritised in schools, resulting in a neglect of more overt discussion about emotional health. Topics the young people named as important in their PSHE were discussions surrounding understanding feelings, coping with emotional distress, and accessing support. Hence it is clear again from Kidger et al. (2009) that young people do have strong views about their mental health needs. Some young people also expressed caution about the sensitive nature of discussing their emotions in class and would prefer smaller group discussion with professionals to ensure confidentiality.

Kidger et al. (2009), however, similar to Armstrong, Hill & Secker (2000) focused their discussion on emotional health and purposefully avoided discussion about mental illnesses. The direction provided in these focus groups was from an adult perspective in terms of working within a set curriculum agenda for young people. There was no allowance for young people to enter a discussion about mental illness, which was not acknowledged as relevant to young people. The relevance of discussing mental illnesses has however not been determined by the young people themselves, so how do we know it is not relevant? The danger of professional agendas can easily obscure young people’s views and opinions.

In fact, there have been a few research studies that have shown that young people have wanted to know and are interested in knowing about specific mental health illnesses. In Williams & Pow’s (2007) cross-sectional survey of 496 Scottish teenagers, it was found that there was interest expressed in wanting more information about manic depression, personality disorder and schizophrenia, which they felt they had little knowledge of. The results of this study were influenced by how the young people understood the mental illnesses that were listed in the questionnaire provided, and there was a specific expectation that the young people would select certain categories that they would like more information on. There was no opportunity available to explore or understand the reasons why young people wanted further information about these specific illnesses. The assumption made by Williams & Pow (2007), therefore, was that the young people were familiar and aware of the diagnostic language used.

In Woolfson et al.'s (2008) study 44 young people participated in nine focus groups to discuss issues related to the provision of mental health education. During these discussions, young people aged 11-17 explored how the sessions could be delivered by school staff and external professionals, the location of the sessions, preferred groupings, level of engagement, curriculum coherence and what was thought to be useful content. This included information about depression, eating disorders, sexual health problems, self-harm, autism, ADHD, dementia, and schizophrenia. The young people wanted to know how these conditions could be prevented and what coping strategies were available to support individuals with these conditions. In contrast to previous research discussed, Woolfson et al. (2008) acknowledged and focused on the importance of young people's opinions regarding the provision of mental health education. Woolfson et al. (2008) also believed that if young people's opinions are considered then there will be an improvement in the relevance of the application of mental health education for young people.

Woolfson et al. (2008) have illustrated that young people have a strong and justified voice concerning their mental health education needs, which appears to contrast adult concerns about the young people's emotional health. More relevance and value has been placed by young people on mental health education to improve their literacy about specific mental illnesses. Particularly noteworthy is the opportunity Woolfson et al. (2008) has given to allow young people the chance to discuss mental illnesses. The problem with this research remained in the inability for the young people to focus specifically on how the mental health education provided could improve young people's knowledge and understanding of specific mental illnesses. The specific problems or illnesses named by the young people in Woolfson et al. (2008) are broad in nature and do not take account of the specific requirements needed in young people’s literacy needs. More research should focus on what young people’s educational needs are related to these conditions.

The results of these studies have indicated young people have the ability and voice necessary to direct their requirements and an interest towards a MHL intervention which involves increasing their knowledge and understanding of specific mental illnesses. Moreover, young people have expressed dissatisfaction with the current provision of MHL interventions within secondary schools (Kidger et al. 2009; Woolfson et al. 2008). The consequence of applying an adult-led agenda within schools that is not relevant to young people’s needs will be an increasing level of resistance and lack of interest.

Research that has considered the views and opinions of young people about their MHL needs has significant gaps that this research intends to fill. A quantitative approach does not allow young people to explore their views and opinions enough within a rigid framework of a survey. However, even when research allowed more flexibility through focus group and individual interviews, the term ‘mental health’ has remained interpreted within an adult-orientated perspective, where there has been active avoidance of any discussion of mental illness. The exception to this was the study of Woolfson et al. (2008), which did allow young people to discuss their literacy needs in terms of the different mental illness diagnoses. There is further need for young people to enter a dialogue that considers the meaning attached to a specific mental illness. Breaking the silence on these taboo topics could enable young people to explore their MHL needs without fixing them within an adult-orientated perspective (Bulpitt & Martin, 2010).

2.5 What gaps need addressing?

From this literature review, there are clear indicators that further research should appreciate the social construction of young people’s knowledge and understanding that surrounds the experience of psychosis. The approaches used in the literature so far have not given enough consideration to the complexity of terminology used within the literature, and how this has influenced interpretations of young people's MHL.

Literacy interventions have varied in motive and have not appreciated young people's needs enough. No opportunity has explored young people's MHL needs without an adult present. Dialogue engaged by young people within the research literature has been directed solely by ARs. From a social constructionist perspective, to address this gap would be an invaluable asset to understand the meaning attached to young people's psychosis literacy needs.

Greater depth of questioning and critical discussion on key theoretical concepts in the field of MHL should be explored. The research evidence reviewed in this chapter has taken these concepts for granted. Hence, I will now devote an entire chapter to challenge and explore these concepts to explain to the reader the direction this research has taken.

Chapter 3: Theoretical Background

In this chapter, a critical discussion will centre on an exploration of the meaning of mental illness to help the reader understand and appreciate the professional disagreement towards applying a biomedical model in creating a psychiatric diagnosis. The value of lay knowledge about mental health will then hopefully shine a new light to appreciate the meaning given by young people towards their understanding of mental health.

The previous literature review often overlooked the value and positioning of the young person’s voice as concerns focused on young people’s illiteracy and stigma. This is an important stepping stone that this thesis stands upon to guide potential developments to improve young people’s psychosis literacy.

3.1 Psychiatric understanding of Mental Illness

The medical model or process of medicalisation presents mental illnesses as the same as another physical illness. It has dominated the diagnostic language used to describe mental illness within the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM) and in the Mental and Behavioural Disorders chapter of the World Health Organisation’s Classification of Diseases and Related Health Problems (ICD). Despite the dominance of this understanding and assumptions made based within this medical framework, there remains widespread critics of such a process. The level of such criticism demonstrates an underlying flaw in using a medical diagnostic criterion to determine levels of young people’s literacy. An overview of the different theoretical frameworks that have been used to understand mental health experiences will now follow.

3.1.1 Positivism

Positivism has had a wide influence on Western philosophy which has focused on reason and scientific progress as its source of knowledge and, when applied to human behaviour and experience, these factors objectively describe universal causal terms across time and place (Bhaskar, 2011). Predictions and explanations of why this behaviour or experience has occurred are within the role of scientific reasoning.

An example of how this theory has been applied within the field of mental health is within the stress-vulnerability hypothesis, which has been significantly influential within the fields of psychiatry and psychology to explain the result of mental illness due to biological vulnerabilities and various levels of environmental stresses or life events. These variables have been treated in a scientific and objective manner, which unfortunately limits appreciation towards understanding the complex nature of humans existing as social beings. To understand social variables such as gender, age, class, or race as fixed and measurable is neglecting attention that needs to attribute the historical, symbolic, cultural or contextual meaning involved. In relation to the stress-vulnerability hypothesis, this has an important influence when considering the possible nature of stress involved in individual's lives, such as power relations determining interpretations of mental illnesses.

The presentation of biology as an independent source of behaviour and emotional distress has also neglected consideration of how the biological make-up of the body is continuously shaped by social action. The focus on solving the biological causes of mental illness through medication and monitoring of symptoms has had the consequence of not considering the lived experience of the individual. Within the field of health psychology, Stam (2000) argues that there is a need to question definitions of health and illness, and stop being subservient to biomedical theory and instead start listening to the patient's experiences.

Discursive approaches in health psychology focus on the person's experiences and feelings as a central concern against traditional biomedical models of health and illness (Yardley, 1997). The concept of feelings has been explored by Cromby (2015) to illustrate the historical, cultural and social meaning that they can hold. Thoughts are not entirely a personal activity but are influenced by changing cultural and social context (Billig, 1991; Henriques et al., 1998; Shotter, 1993). The benefits of using a discursive approach in Stoppard (1999) allowed a feminist perspective to develop when understanding and treating depression. The material and social conditions of women's lives require further examination and should not be ignored when working within a biomedical model.

Positivism is based on the need for objectivity. This is difficult to apply when considering the structure of beliefs and assumptions that influence how mental illness is viewed and understood. Quantification and measurement of people’s thoughts, feelings or behaviour can dangerously lead to assumptions that these measures can represent the structure of these thoughts, feelings, or behaviour without any reference to the social context they lie in (Danziger, 1985). Critics have remained firm that any scientific enquiry involves a view from somewhere but this is often dismissed due to concerns over the need for scientific validity and objectivity. Hence, the voice and experience of service users became interpreted as the weakest form of evidence, but the strongest challenge to the process of medicalisation in psychiatry. The field of Mad Studies has been at the forefront of increasing the credibility of service users as the experts of their own experience of mental illness, which is in direct opposition to notions of the hierarchy of knowledge within evidence-based practice (Beresford, 2016; LeFrançois, 2016).

Finally, the framework of positivism is firmly based on considering the symptomology of mental illness, which views and understands behaviour as a dysfunction of the brain and body. Such a viewpoint has a significant flaw in potentially leading to a reductionist explanation of human experiences. The explanation of schizophrenia, for example, becomes based on a biological chemical imbalance dopamine hypothesis, or psychological reasons based on the experience of childhood trauma, or even social causes such as poverty and class. The nature of this causality is far from conclusive. The factors influencing human behaviour are multiple, complex, and interrelated, as personal meaning of the lived experience of the individual will certainly be influential. Hence the need to build upon the context and meaning of the experience must make it intelligible (Ingleby, 1981). This is contrary to the DSM that conceptualises each ‘primary mental disorder as an autonomous medical disease whose identification in no way depends on investigating the patient’s personal history’ (Jacobs & Cohen, 2010, p314). The term ‘reification’ appears to be appropriate through medicalisation. Problems remain with the inability to distinguish mental illness experiences from intelligible and culturally sanctioned responses to misfortunes in one’s life (Jacobs & Cohen, 2010).

The influence of medicalisation in terms of psychiatric classification and diagnosis is certainly not conclusive or problem free. In fact, what has been proven is that there is widespread criticism that exists against the use of such a framework. This supports the need to question the use of such a framework within the development of MHL strategies. The next part of this section will be to discuss what alternative theoretical frameworks have existed which do not conform to such medicalised diagnostic understandings of mental illness. These various philosophical perspectives may highlight an alternative framework to work from when interpreting and considering young people's literacy about the experience of psychosis.

3.1.2 Cognitive approaches

Cognitive approaches involve understanding what personal meaning exists when individuals interpret their mental health experiences. The interpretation of this meaning will determine the response shown by the individual. Childhood traumatic experiences activated by critical incidents, for example, result in experiences of mental illness.

However, a positivist epistemology still exists within the science of studying cognition. The focus on objective reality against irrational emotions involved in human behaviour has been promoted through the treatment of Cognitive Behaviour Therapy (CBT) for schizophrenia. The need for evidence to illustrate the objectivity of the therapy in treatment supports the positivist framework previously discussed. Fault centres on internal mental mechanisms, empowering individuals to have the ability to overcome an individual's emotional response.

Such an approach has altered how one can explain psychotic experiences, as Bentall (2003) puts forward an alternative paradigm called a 'complaint-orientated' approach. Bentall (2003) supports his approach with psychological research that has explained how auditory hallucinations can occur when an individual mistakes inner speech for an external stimulus, and abnormal inferential processes have produced delusional thoughts. In this context, the experiences of psychosis can be related to more readily and the application of psychological therapies have developed in terms of targeting auditory hallucinations (hearing voices) and supplying an alternative treatment to antipsychotic medication (Thomas et al., 2014).

Dialogical approaches have tried to illustrate how cognitive thoughts are not stable properties of an individual’s mind but are ongoing constructions of the self and social relationships. For example, Clarke (2015) comments on the importance of applying an emotion-focused formulation approach to enable individuals to express their emotions within the everyday, jargon-free language that sees mental health problems in non-diagnostic terms. The problem remains that meaning-making still relies on the use of psychiatric diagnosis and focus is limited to an individual’s interpretation of the current reality of their cognitive thoughts. There is a lack of appreciation of the social context involved in the individual’s life, such as domestic violence, poverty, or housing.

3.1.3 Radical behaviourism

Radical behaviourism founded by B. F. Skinner, is based on the notion that the study of the science of behaviour is possible by understanding and analysing behavioural events in relation to past and present environment (Baum, 2011).

Hence, even private acts and experiences, such as thinking and feeling, are understood contextually as a part of human behaviour which changes through interactions with our environment. The meaning attached to psychotic symptoms is understood within this context and needs to be considered in terms of how people do not respond automatically to such experiences but behave in ways that are goal-seeking, purposive and functional.

The unintelligible characteristics of psychosis can then become more understandable when more is known about the environments and consequences that shape the individual’s behaviour. For example, delusional beliefs do serve an important function in people’s lives and can be understood as an adaptation to their particular environment. The adaptive response considered is associated with the basic human need to make sense of one’s condition to attribute meaning to experience (Roberts, 1991). It is not simply characteristics or symptoms of a disorder that destroys meaning but, alternatively, it is purposeful for that individual.

3.1.4 Interpretative or hermeneutic approach

The hermeneutic tradition has understood human activity as having a purpose, meaning and agency, and not being governed by the outcome of causal forces. The individual's behavioural response will influence what sense they make of the event. The individual creates meaning shaped by their personal histories and their social and cultural context. There is no universal response. Hence, the use of diagnostic categories from this perspective significantly limits an appreciation of the behaviour and experience of mental illness.

Laing, one of the so-called 'anti-psychiatrists' presented hermeneutic attempts to interpret the symptoms of schizophrenia in an intelligible and meaningful approach. Laing's work, starting with the 'Divided self' (1960) and 'Sanity, Madness and the Family' (Laing & Esterson, 1964) centred on trying to understand and treat schizophrenic patients. Laing had a deep-seated interest in exploring the subjective experiences of being a schizophrenic, in which he criticised the limited and inadequate definitions placed by psychiatry, feeling that too much focus was placed on looking at the experience from the outside and not exploring the lived experience of schizophrenia (Laing & Esterson, 1964).

Thomas Szasz's 1961 book, The Myth of Mental Illness, based his argument that problems of living should not exist within a disease model framework. Szasz (1961) argued that it is wrong to diagnose and use a medical model to understand human struggle and difficulties, which he called the process of 'medicalizing morality'. Psychiatry was seen as having a coercive role to sanction the use of involuntary hospitalizations and psychotropic medications, thus monopolising judgements of normality and what is disease. The creation of diagnosis was the process of turning towards experts for a solution to human experience that society cannot tolerate or explain, and to alleviate society's fears through a reliance on experts to supply an explanation and solution.

The question raised by the hermeneutic tradition is how we uncover the meaning of an individual's subjective experience. Psychoanalysts put forward the argument that meanings can be understood through an examination of an individual's inner emotions, hopes, fears, dreams, and nightmares. While phenomenology aims to discover the subjective nature of one’s experience without shaping interpretations in a more objective experience. These approaches favour therapies that find meaning in human experience but are still limited by working within diagnostic categories.

3.1.5 Constructionism

Constructionism focuses on how individuals impose meaning and make sense of their lives. It has its origins from Piaget (1978) and has been influential in interpreting human beings as concerned with making meaning.

The meaning that the diagnosis of psychosis potentially has on an individual is therefore shaped by their own experiences and reflections of what this will mean on the individual’s life. This meaning is dynamic and contextual depending on how one learns and reflects on their experience.

3.1.6 Social constructionism

Social constructionists question taken-for-granted concepts used in everyday life which, when applied to psychiatric diagnoses, views their formation as a linguistic construction developed by social groups. It questions the essentialism of these diagnostic categories, as they are constantly evolving and unstable concepts that are historically, socially, and culturally specific. Social constructionists are therefore interested in how mental illness is subject to change in social norms.

In relation to psychotic experiences, the experience of hearing voices has been interpreted historically in religious terms. Social attitudes have changed to how these experiences are valued, or in this case devalued, as a diagnosis. Similar changes of attitudes occurred when homosexuality was removed as a diagnosis from the DSM in 1973 due to civil rights campaigns. The social process of deciding psychiatric diagnosis is dominated by professional decisions whether to change diagnostic categories. These decisions are not based on any empirical evidence but rely on credibility and validity decided and sustained by social processes. There is a need for diagnostic terminology to be sanctioned within a cultural and historical context, and cannot be identified as real or absolute, but exist within a post-structuralist understanding of the world.

3.1.7 Critical realism

In contrast, there is an acceptance within critical realism that there is a real world out there (positivism), but that there are competing views of the world across time and space in which humans make a judgement what is true about their world (constructionism) (Bhaskar, 1986).

When applying this philosophical perspective to the creation of diagnostic labels in mental illness, it rejects the positivist notion that facts can be separated from the values that have created these labels. In other words, the judgements made to formulate a diagnostic criterion is interest driven, without any ontological and empirical standing. In relation to experiences that have been labelled as schizophrenia, a critical realist would accept that people do hear voices or hold thoughts and beliefs that do not make sense to others, but that these experiences are not a mental illness or called schizophrenia, but are experiences considered abnormal by others (Pilgrim, 2015). The experience of hearing voices could alternatively display the ability for humans to have the capacity to experience imaginary events as real, shaped by an individual’s experience and social and cultural context (Boyle, 2002).

3.1.8 Process philosophy

Process philosophy emphasises the need to be concerned and focused on what is occurring in a world that is in constant change and not on perceived stable entities. Human experience is constantly shaped and changed and emerges through the association of processes involved in the creation of concepts (Chalmer, 2006).

Psychological experiences are continuously processed, which challenges the static diagnostic criterions traditionally used to label mental illness. Instead, process philosophy emphasises the need to appreciate the complex entanglement involved in relationships between biological, psychological, and social influences which together create the experience of the individual. The multiple combinations of influences involved in this process will produce different meanings and responses, which will then contribute to the next response the individual will display.

Emphasis on the principle of becoming rather than being fits a more Eastern philosophical framework of understanding how everything is tied together (Mesle, 2008). Everyday actions and experiences are bound within a process of interconnected social structures and cultural resources that shape how it is understood and explained. The meaning attached to the experience of psychosis is not fixed and must be interpreted within the dynamic social structures and relations they exist within.

3.1.9 Systemic approaches

Systemic approaches aim to broaden the focus away from the individual towards a wider social network involving the family or social group. The aim is to enable one to investigate what problems are involved in the interaction of this social setting. There is an underlying assumption that problems are found within the interaction of family members, and thus requires exploration to understand the meaning and purpose it has created.

From this approach, the interpretation of mental illness widens in terms of the meaning and change such diagnosis may have within the relationships formed in the family. This will involve consideration of how shared meaning is formed through the language used and joint construction of understanding between family members (Dallos & Stedmon, 2014). Thus, this increases emphasis away from expert theories and judgements, and places more appreciation on how an individual’s problems have an impact and function within social groups.

3.1.10 Spiritual perspectives

The spiritual or religious perspective of understanding the experience of mental illness has had a contrasting viewpoint to traditional notions given by a psychiatric diagnosis. Some service users have welcomed the understanding provided by a spiritual dimension of their psychotic experience as a way that can offer lower distress levels (Brett et al., 2014).

The reason spiritual perspectives can reduce distress is through the opportunity that service users felt that there was greater perceived social support and understanding available, with greater perceived controllability and less stigmatising responses when interpreted in a spiritual manner (Brett et al., 2014). The result has led to the ‘Emerging Proud’ campaign which has aimed to speak about experiences such as hearing voices with deeper spiritual meaning without being pathologized (https://emergingproud.com/).

The ability to recover within this perspective has a different meaning and purpose. Heffernan et al. (2016) considered the role of religion in recovery from psychosis, where service-users illustrated the benefits associated with mindfulness and supporting meaningful activities, while self-blame, guilt and alienation were also a consequence. Whereas, Heriot-Maitland et al. (2012) illustrated the advantages of helping people with psychosis re-connect the meaning of their out-of-the-ordinary experience, as the normalisation effect can reduce stigmatisation, improve therapeutic alliance, combat distress, and increase hope of recovery. Thus, this supports the justification made by Kingdon & Turkington (1991) to treat schizophrenia with cognitive behavioural psychotherapy.

From this perspective, a continuum of psychosis broadens the meaning of the experience of psychosis. It allows the experience of psychosis symptoms to be prevalent in the general public without needing to be medicalised, thus allowing them to be understood on a continuum with normality (Verdoux & van Os, 2002).

3.1.11 Liberation and social justice approaches

From a more practical approach, the liberation and social justice approaches recognise the role of social structures, interests, and power in the production of knowledge and practice that it supports.

In this approach, the influences of gender, race and poverty are part of social injustice that requires rectification in terms of how it is influential in determining the process of medicalisation of mental illness experiences. The more privileged on the other hand will try and maintain power. Hence the use of mental illness terminology and language can be one tool capable of legitimising members of a disadvantaged group as suffering from a mental illness rather than suffering from social injustice.

Liberation psychology attempts to address this inequality by opening up a further dialogue with these disadvantaged groups to enable them to critically reflect on their personal experiences. Paulo Friere is a key figure in heading this process, seeing the need to stand alongside marginalised groups to take social action, a process of transformation against social oppression (Afuape & Hughes, 2016).

Mental illness is therefore understood as an intelligible response to inequalities of power and resources. The interpretation of the experience of hearing voices is not a symptom but an experience utilised to reduce distress and create comfort and encouragement, supplying meaning in their lives. The interpretation of treatment is not medically orientated but focused on solving the power issues at play in people’s lives. It reflects the need to recognise and identify an organisational and social change to rectify social injustice (Bostock & Diamond, 2005).

3.1.12 Experience and expertise

Related to the social justice approaches discussed above has been a movement towards efforts in empowering those individuals marginalised within society. In the field of psychiatry, this has focused on efforts to hear the voice of the service user lost by the superiority and dominance of knowledge production within psychiatry and psychology. The emphasis on objectivity has diminished the importance of gaining a more subjective understanding of the individual’s experience.

For example, the value of understanding the content and nature of what the voices are saying when someone hears voices is an important consideration when understanding the meaning attached to this experience. A symptoms assessment is not simply required (Boyle, 1996). Foucault (1967) points out a diagnostic framework can reduce problems experienced by service users as untrustworthy with evidence of lack of insight.

The importance of valuing the expertise of experience has challenged traditionally-held notions attached to the expertise within psychiatry. ‘Epistemic injustice’ and structural discrimination has silenced and devalued the worth of these personal stories (Fricker, 2006; 2007; Russo, 2016). The Hearing Voices Network is an example of how voice-hearers now work as peer facilitators and the creation of Mad Studies has validated the expertise of service users (Russo & Sweeney, 2016).

3.1.13 Feminist perspectives

Feminist theory has been strongly critical of the psychiatric diagnostic system. It has advocated its belief that the use of diagnosis has inappropriately pathologized women’s reasonable responses.

Specific criticism is charged at the role of psychiatry in pathologizing women as less rational, less stable, less intelligent and less mature, and have made links to women’s biological nature as a reason for their behaviour, such as premenstrual dysphoric disorder – characterised as ‘difficult’ women (Ussher, 2013). There is also a long history associated between diagnosed female malady associated and hysteria in the 18th and 19th century, and later termed as borderline personality disorder, within the DSM as linked to the essence of femininity and specifically related to the ‘seductive’ nature of women (Ussher, 2013).

The difficulty for women has been the inability to challenge the language and power held within the existing psychiatric framework of knowledge and understanding. The aim is to acknowledge this abuse of power, and the level of oppression that has resulted, and validate women’s experiences of courage and survival. Similarly, for therapists, empowering relationships are fundamental (Miller, 2008). In terms of language, a revision of symptoms such as voice-hearing could become a survival strategy (Gilligan, 1981). Kate Millett’s own struggle against psychiatric confinement also illustrates an invaluable insight into the type of injustice, betrayal and sexism portrayed against psychiatry (Millett, 2000).

3.1.14 Indigenous Psychology

Indigenous psychology recognises that there is a need to appreciate and consider people in their own context, and not to rely on a Western context to interpret mental illness experiences. The aim is to avoid Western discourse, and instead interpret the experience of mental illness that relates to their own shared group (Kim et al., 2006; Dudgeon & Bray, 2016).

The value of exploring indigenous healing practices provides the means of considering the multiple perspectives involved. This can then avoid interpretations of mental illness becoming culture-bound and limited to dominant Western psychiatry (Dudgeon & Bray, 2016).

3.1.15 Narrative approaches

Narrative approaches have emphasised the need to take a more personal interpretation of the lived experience of mental illness (Ricoeur, 1991). It is through the interpretation of narratives that understanding is achieved, as explanations can be clarified and agreed (Frid et al., 2000). This approach has challenged traditional means of interpreting risk within the mental health setting (Felton & Stickley, 2018). The importance of engaging in dialogue with others is essential to explore how meaning is created when understanding human behaviour and experience.

3.1.16 Alternative perspective to medicalisation and diagnosis – the Power Threat Meaning Framework

The previous summary of different philosophical outlooks taken regarding the understanding of unusual experiences has illustrated the complexity involved when considering the meaning attached to the diagnostic label of psychosis. It has challenged existing concepts of pathologizing these experiences and emphasised instead the need to understand abnormality within a continuum with normal behaviour and experience. These experiences require consideration within the context of relationships humans form within a socio-economic, cultural, environmental, and material context.

An alternative framework to the psychiatric diagnosis has been the Power Threat Meaning (PTM) Framework (Johnstone et al., 2018). This framework was co-produced with service users and has allowed traditional symptoms of mental illness to be interpreted as threat responses to the different powers that exist in people’s lives. These difficult experiences posed upon individual’s lives are made sense of and given meaning as part of their society in relation to how we may feel in terms of shame, self-blame, isolation, fear, and guilt. The framework increases recognition of how individuals can survive these threats, by focusing on and promoting skills and resources individuals have to overcome within these wider social factors and traumas. The consequence is that the PTM Framework is more accepting of the wide-ranging strategies people can utilise in order to survive and protect themselves.

The PTM Framework hence creates a new perspective beyond the individual and shows that we are all part of a wider struggle for a fairer society. This indicates that there are common ways people are likely to respond to certain kinds of threat, which supplies the opportunity to accept and confirm the experiences related to mental illness. It is then hoped that mental health services can then take account of these personal stories to meet their needs and provide access to support without being dependent on having a diagnosis. Thus, increasing respect to the creative and non-medical ways of supporting people across cultures.

The importance attached to specifically developing an understanding of the meaning and narrative attached to the experience of psychosis is a prominent feature throughout these philosophical perspectives. Consequently, when assessing young people’s literacy about psychosis, a broader acknowledgement to the variety of meaning that this can take, not limited within a DSM diagnostic framework, is required. The value of lay knowledge of mental illness challenges the dominance of professional discourse surrounding psychiatric diagnosis. This will be central in my thesis to understand how one can cater to young people’s literacy needs.

3.2 Lay understandings of Mental Illness

Different theoretical approaches have been used to try and explain how lay people explain behaviours that are considered mental illnesses. It is important to examine these theories to assess whether they are adequate to understand how lay people formulate their discourse about mental illness, specifically focusing on behaviours related to the diagnostic term psychosis.

Overall, a noticeable theme throughout these theories is how they try to understand why lay knowledge involves beliefs and attitudes that either do not conform to professional knowledge or have led to an increase in stigma and discrimination towards those with a mental illness. An evaluation of lay knowledge exists against a set of professional theories considered to be based on empirical scientific evidence. Holding such professional knowledge in such a high regard undermines and undervalues the value of lay knowledge. The consequence is that an agenda to improve such lay knowledge determines the measure of success or failure in educational programmes.

The need for further appreciation and credit to value lay knowledge on its own terms should consider the social context of dialogue about mental health and illness. One should not neglect to consider the influence that youth culture has when considering young people’s knowledge and beliefs. The benefit of such an approach avoids discrediting lay knowledge from a professional perspective. I will now consider each existing theoretical approach in turn and appraise how these theories can enable lay knowledge to be understood.

3.2.1 MHL

The first approach considered will be the MHL (Mental Health Literacy) approach, which focuses on the knowledge and beliefs about mental disorders which aid their recognition, management, or prevention (Jorm et al., 1997). Jorm et al. (1997) was concerned with examining the ability that the general population displayed in being able to recognise specific disorders. Emphasis on the identification and classification of disorders reduces the definition of mental health to a diagnostic interpretation of human behaviour. There is a lack of consideration of mental health as a wellbeing concept.

Studies that have examined the extent of lay MHL have determined those who are illiterate as not having the ability (or refusing) to endorse professional knowledge about specific mental disorders. This act of not taking up expert views of mental disorders therefore lacks knowledge and understanding. The MHL approach stands firmly in the belief that there is a correct form of literacy needed to help better recognition and diagnosis. The result of this identification is believed to lead to a correct identification of risk factors and causes, better self-help interventions, recognition of appropriate help-seeking behaviour and knowledge how to seek mental health information.

The result of this approach is that it neglects to consider any alternative perspective held by the public that does not agree with the status quo held by professionals. In terms of recognising what correct help is available, there is potential for lay knowledge to be discounted as illiterate and to not try to understand the reasons involved in why this form of help-seeking is perceived as most appropriate. The cultural and social dimensions that are involved in such decision making are discounted.

3.2.2 Lay theories of schizophrenia

Furnham & Rees (1988) have explored lay theories of schizophrenia to illustrate that lay people do have a well-developed theory of the causes of schizophrenia. Furnham & Rees (1988) based lay theories on whether there was an acceptance of established academic theories to explain schizophrenia. Siegler & Osmond (1966) set out several dimensions/models of modern scientific theories of the causes of schizophrenia, compared and interpreted alongside lay beliefs about the nature, causes and treatments of schizophrenia.

Lay theories of schizophrenia have helped develop an appreciation and understanding behind the reasons how the public perceived schizophrenia by the extent to which they endorse biological, psychological, or sociological theories for the causes of schizophrenia. Accordingly, Furnham & Rees (1988) have illustrated that the extent to which the public form their attitudes towards individuals with schizophrenia is determined by what type of model they use. For example, the preferences to use environmental explanations (such as social stresses), rather than the medical model, reflect the motives in the community health movement. Lay people have had the ability to explain schizophrenia within a psychosocial model (related to stress and pressure), successfully preventing associations of schizophrenia with the characteristics of necessarily being dangerous.

Alternatively, attitudes that individuals with schizophrenia have learning disabilities is linked to a cognitive deficit theory, and perceptions of being dangerous, unpredictable and erratic were linked to perceived misconceptions of its link with the term split personality. This misconception was based on schizophrenia being seen as a disorder that the public would be less able to empathise with, as it is less common and less understood. The dominant medical model also explained why individuals with schizophrenia would be viewed as patients, be treated within a hospital, have a diagnosed prognosis, and be expected to be treated.

These lay theories allow an assessment to be made about the extent which people understand the causes of mental illness, thus assessing the success or failures of educational programmes. When lay knowledge does not conform to the set out academic theories to explain schizophrenia, there is a belief that this form of knowledge could lead to negative attitudes. There is a danger, however, that this approach satisfies an agenda that assumes that professional have an accurate and fully-formed understanding of causation – which itself is contestable – and neglects the perceived needs of the young person.

3.2.3 Lay Attribution Theory

Attribution theory is a framework used for explaining stigmatised attitudes and discriminatory behaviour (Weiner, 1995). The theory proposes that people make attributions about the causes and controllability of a person’s illness. These attributions create inferences about the extent of responsibility the individual has about their illness.

Central to this theory is the assumption that when someone is presented with a mental illness, people try to decide who is responsible for the behaviour demonstrated. Attributions are made about the causes and controllability of the event so that judgements can be made about the extent to which the behaviour is within the individual’s control. Perceptions of dangerousness, violence and unpredictability can increase social distancing and segregation if the individual is blamed as being responsible for their actions.

Martin, Pescosolido & Tuch (2000) showed how the effect of attributing certain causes of schizophrenia can change lay attitudes towards these individuals. Causes such as chemical imbalances, genetic factors or stressful life events can reduce the attribution of the illness caused by having a bad character, the manner of how you were raised or even ‘God’s will’. These internal causes can lead to increased social distancing, while external causes can decrease the level of social distancing towards the individual.

This theory supports the proposal that educational initiatives should prevent lay knowledge from attributing the causes of psychosis to internal causes as described above. These initiatives would then prevent negative attitudes from developing against individuals, improving the level of social distancing. One strategy suggested would be to increase the biomedical perspective of psychosis, treating it as an illness like any other physical illness.

This approach reduces an appreciation of the variety of possible different causes of developing psychosis. It also places a large assumption that everyone’s cognitive process will be the same when they are trying to understand the experience of psychosis. There exists naivety that by considering psychosis as externally influenced that negative attitudes will decrease. Instead there may be a greater feeling that recovery is not possible and that it is out of the individual’s control, increasing anxiety of unpredictability. Whereas, if causes were more external, then chances of recovery could be greater as the individual will have more control over getting better and do not appear to be out of control.

When this theory has focused on considering the probable causes of psychosis and the level of responsibility for their behaviour, the cultural and social context of understanding the experiences of psychosis becomes neglected. For example, the language used to describe psychosis, the type of imagery used to describe someone with psychosis, the role of the individual within society or understanding the lived experiences of psychosis requires further exploration.

3.2.4 The Folk Psychiatry model

The theoretical model named the folk psychiatry model has attempted to broaden and appreciate the complexity involved in understanding how lay people comprehend mental illness. The aim was to overcome the limits placed by explanations set via the traditional attributional model, which supplied only two dimensions involving controllability and stability (Haslam, 2003; 2005). This understanding was too simplistic and reductionist when considering the complexity of meaning and understanding credited to lay people’s knowledge and understanding of mental illness (Haslam, 2003; 2005).

The folk psychiatry model supplied instead a dimensional model to acknowledge the complexity involved in lay knowledge, illustrating the multifaceted explanations developed. Lay knowledge involves individuals actively constructing their understanding of mental disorder through a process of pathologising, moralising, medicalising, and psychologising. Each of these dimensions shall now be considered in turn.

3.2.4.1 Pathologising

In summary, the folk psychiatry model explains that lay people understand mental illness by first pathologising the behaviour displayed. This process explains how behaviour is perceived as abnormal, aberrant, or deviant, and is the starting point for lay people to develop an explanation to understand why the norm has been disrupted. First, a judgement must be made that the behaviour is abnormal because the experience is either viewed as rare or unfamiliar or deemed culturally or interpersonally inappropriate. This judgement needs to be made in order for lay people to start the process of explaining what possible reasons there are for this behaviour, for example is this caused by internal or external causes. Finally, lay people compare the behaviour with normal behaviour, which confirms that the behaviour is abnormal (Haslam, 2005; 2007).

Pathologising assumes that the behaviour lies within the realms of a Western psychiatric biomedical model, discounting any alternative meaning of abnormal or deviant ways of behaving. The drawback of this assumption is that the model does not allow, or consider, the possibility that lay understandings of mental illness do not enter the process of pathologising. The extent that lay understandings allow mental illness within the continuum of normality is a question that is not often considered as possible.

3.2.4.2 Moralisation

The approach of moralising involves a similar process described in the attribution theory, in which a judgement is made on the extent of responsibility that is attributed to the behaviour demonstrated. The difference within folk psychiatry is that there is a focus on discovering the reasons why it may be immoral (Haslam, 2005; 2007). Examples of this process have occurred when considering the reasons why someone may engage in substance misuse or have an addiction. The responsibility for engaging in such behaviour could be immoral, as the individuals are blameworthy for choosing to engage in such behaviour.

However, questions about the process of moralisation need to be considered. Moralisation involves the judgement to hold the person morally responsible for their behaviour since they have control over their actions and are therefore blameworthy. The reason behind this behaviour may be based on having bad intentions or inadequate self-restraint or willpower (Haslam, Ban & Kaufmann, 2007). This judgement is not possible if the behaviour is accepted and normalised within society, as this takes away the belief that the behaviour displayed is morally against social norms. Consequently, moralisation will depend and change depending on social values among different individuals, such as by asking who is making the judgment?

The different justification developed within lay knowledge shows an important consideration in the development of attitudes towards certain illnesses. If someone is morally responsible for their behaviour, then the consequences could be decreasing levels of empathy and more willingness to enforce punishments and segregation against these individuals. However, this is not as clear-cut as one would imagine. Having responsibility for your behaviour does not necessarily mean that your behaviour is immoral. The subjective nature of morality creates a question mark over such generalist claims of thinking from a lay perspective. Instead, having responsibility for your behaviour could give the individual a chance to take control of their lives and could create more criticism against society's attitudes towards an individual's mental illnesses.

3.2.4.3 Medicalising

Haslam (2005; 2007) confronted the moralisation dimension by suggesting that a Western medical framework can take away moral responsibility from the individual. This dimension, termed as medicalising, occurs when explanations are based on somatic factors outside the control of the person. One is unable to choose or even change their circumstances. This dimension is analogous to other types of physical health diseases. Genetic or chemical imbalances in the brain are the most common explanations, mirroring the dominant explanations provided by modern psychiatry, but focusing specifically on the causes of the unintentional behaviour.

Haslam (2005; 2007) argues that such explanations can lead to mental illness being seen as 'natural kinds', outward expressions of an inherent pathological essence distinct from normality that is not socially shaped. This explanation goes against the possibility that mental illness exists within normal lived experiences and is able to relate to such experiences. Such an explanation is not necessarily welcoming or helpful in terms of enabling individuals to seek help or engage actively in society again, as the diagnosis becomes fixed to the individual (Haslam, 2005; 2007).

The rationale for lay knowledge to medicalise behaviour requires further explanation within this model. The dominance of a biomedical discourse within society does not necessarily reflect the meaning and value held within professional discourse. The exclusion of alternative explanations or interpretations is a possibility within such discourse. While the process of medicalising is dominant, the meaning behind this explanation requires further exploration.

3.2.4.4 Psychologising

The last dimension of explanation is psychologising, where the explanation of causes is more mental than somatic. This involves understanding the behaviour in terms of past experiences, where environmental and social causes are more influential. Mental and emotional responses explain the motives involved in the behaviour. The behaviour is not entirely conscious or rational but shaped by the person's life history, such as childhood trauma and abuse or difficult family dynamics, which can have a considerable influence on explaining the development of mental illness (Haslam, 2005; 2007).

This explanation focuses on causal-historical factors to explain the meaning and reason someone may be acting not according to the social norms. Within this explanation, the moralising aspect of the behaviour is based on external events that have happened to the individual, but is not directed at the individual personally. There is more possibility within this dimension that one can normalise and relate to these experiences, yet the understanding is psychologically abnormal where thought processes are incorrect.

Explaining mental illness through the dimension of psychologising holds similar parallels to medicalising, but favours a professional discourse of psychology. The lived experience of mental illness remains very subjectively experienced and holds wide cultural and social influences that could alter the meaning attributed to their explanations.

3.2.4.5 The 'mixed blessings' of medicalising mental illness

A theme runs throughout Haslam's related research papers that illustrates the disadvantages of laypeople medicalising mental illnesses. Read et al. (2006) conducted a review of anti-stigma programmes for schizophrenia which utilised the approach 'mental illness is like any other illness'. The findings illustrated that such an approach only resulted in creating further fear, prejudice and distancing. Two meta-analytic reviews were conducted by Kvaale, Gottdiener & Haslam (2013) and Kvaale, Haslam, & Gottdiener (2013), the former involving an examination of 25 correlational studies on the naturally occurring associations between explanations and stigma for a variety of mental disorders, and the latter examining 28 studies in which explanations were manipulated experimentally. The results in both meta-analytic reviews revealed that biogenetic explanations reduced the tendency to blame people experiencing mental illnesses but increased the feeling of being dangerous and the desire to distance themselves from these individuals.

In light of these findings, Haslam & Kvaale (2015) were concerned with Schomerus et al.’s (2012) systematic review and meta-regression analysis of studies examining general public attitudes regarding mental disorders before 2011. This is because Schomerus et al. (2012) showed that there was a trend between 1990 and 2006 towards greater MHL based on a biological model of mental illness. Laypeople were increasingly using biogenetic explanations, such as genetic inheritance and brain disease as causes of schizophrenia. However, Schomerus et al. (2012) showed that this did not correlate with any improvement in social acceptance but led to a reduced level of social acceptance towards individuals diagnosed with schizophrenia. Haslam & Kvaale (2015) concurred that the perceived improvement in the public’s MHL through the development and awareness of neuroscience and psychiatric genetics had ‘mixed blessings’ in terms of the effect this had on public attitudes towards individuals with mental illnesses.

Haslam & Kvaale (2015) developed the mixed blessings model to explain how a biogenetic explanation can shape ways of thinking about mental illness. The first positive effect is that it reduces the attribution of blame for the causes of the illness. It is outside the control of these individuals, resulting in more sympathetic responses from the public (Weiner, 1993; Shariff et al., 2014). Haslam & Kvaale (2015) acknowledge that such attitudes do have a positive effect on reducing stigma, however the mixed blessing model illustrates that this is not the only way a biogenetic explanation shapes one’s thinking. The more negative result is the way in which essentialist thinking outbalances the earlier reduction of stigma.

Psychological essentialism is the belief there is a fixed and hidden determining cause for developing a mental illness (Haslam & Kvaale, 2015). The danger of such essentialist beliefs is that it creates biological differences between people, and results in deepening social divides and social stereotypes, increasing the level of social distancing and perceived dangerousness. The fixed, invisible, and deterministic nature of genetic and neurobiological causes encourage a pessimistic prognosis. It does not recognise the socially- or culturally-constructed nature of these categories. The consumption of and exposure to a culture dominated by psychiatric knowledge creates a natural inclination to explain human differences in terms of natural factors. The result is three negative types of attitudes formed towards individuals with a mental illness, only offset by the earlier decrease in the level of blame attached to the behaviour. Figure 3 explains this process diagrammatically:

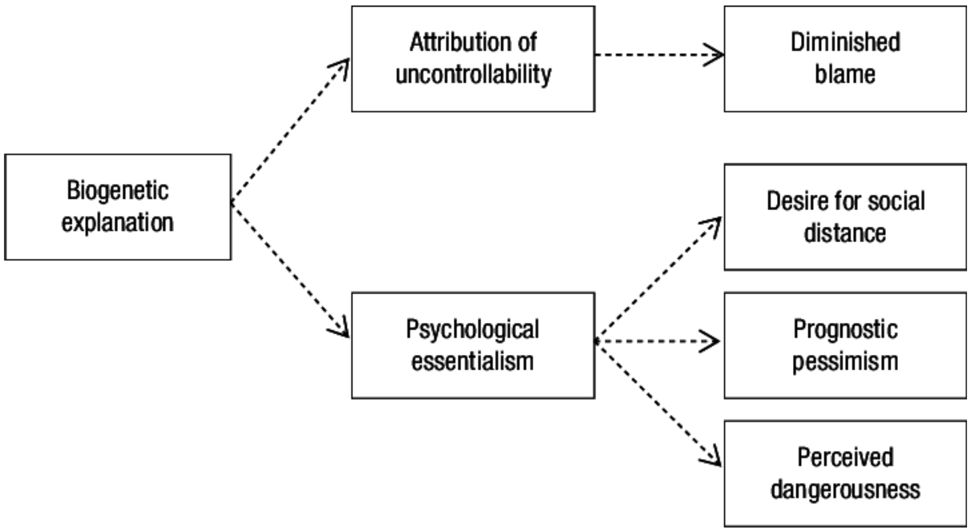


Figure 3: Haslam & Kvaale (2015, p401)

Haslam & Kvaale (2015) accept that it is still important for the development of aetiology, diagnosis, and treatments that biogenetic developments continue. Instead, it was the public which misunderstood and misinterpreted the explanations within an essentialist framework, by not appreciating how these fit within a social, ideological, and intellectual construct. The way forward suggested by Haslam & Kvaale (2015) was to avoid a fixed or deterministic explanation but embrace a much more flexible framework that understood and appreciated the complex social environmental factors involved.

The consequence of Haslam and colleagues' findings has created underlining concern, blame and disapproval on how lay people understand the nature of mental illness from a biogenetic explanation. There is a lack of attention placed on the consequences of how lay people may understand mental illness from alternative dimensions, showing bias towards directing lay people's understanding away from solely a biomedical perspective.

3.2.4.6 The ‘looping effect’ of understanding Mental Illness

Haslam (2016) continues to build upon his argument through the concept of the looping effect. This concept stems from Ian Hacking’s philosophical writing that illustrates that so-called established concepts are not stable entities but do evolve, as shifting sets of ideas and labels which involves ‘making up people’ (Hacking, 1986; 1995).

Haslam (2016) applies this philosophy in how mental disorder has moved horizontally to incorporate experiences once understood as moral failings, personal weaknesses, medical problems (for example, sleep disturbances), foibles or ordinary vicissitudes of childhood. The evidence to support this horizontal expansion examined the increase in diagnostic disorders throughout the changes in the DSM, comparing I, II and IV editions measured by Haslam (2016) in a quantitative manner by reviewing the different diagnostic criteria over time.

Nevertheless, Haslam (2016) did also consider what he calls vertical expansion of the concept of mental illness. This expansion is based on a more qualitative understanding of the criteria needed with a mental illness. The definition provided by the DSM has become less stringent and more inclusive to cater for experiences considered less severe. This form of vertical expansion questions the boundaries between experiences understood to be normal and abnormal. An example provided by Haslam (2016) was a diagnosis of depression, where exclusion from DSM-5 no longer applied if the person has experienced a bereavement. The criterion of the DSM have broadened and deepened the meaning of mental illness in everyday life. This has allowed mental illness to expand as an explanation for problems not earlier considered to be a disorder.

Critics of the expanding concepts of mental disorder have argued that it has led to inappropriate over-medication, exaggerating the estimates of disorders and deflecting scarce resources away from more severe conditions. The increase in biogenetic explanations may result in increased pessimism about recovery and less confidence to control behaviour. However, it may also increase the process of normalisation, as more human experience falls into the realms of psychiatry (Haslam, 2016). Hence individuals perceive themselves and are perceived by others as being less deviant than they would have been before, as the shame attached to the behaviour is reduced. Culturally, lay people's understanding of mental illness may vary according to whether the experience enters the realms of psychiatry or not.

The point made about normalisation is important to consider, as Haslam (2005; 2007) had not considered the possibility that lay people could relate to experiences of mental illness. It is possible that the looping effect of mental illness needs further exploration due to the blurred perceived boundaries within society about what is abnormal and normal. This has a noteworthy influence on discourse about mental illness entering everyday wellbeing needs.

3.2.4.7 Limitations of the 'Folk Psychiatry model'

Haslam (2005; 2007) put forward the impression that mental health professionals shape lay people's understanding of the concept of mental illness. The consequence is that Haslam (2005; 2007) neglected to consider the cultural and social dimensions that have shaped the concept outside the influence of such professional discourse. While Haslam (2005; 2007) acknowledged that the concept of mental illness is dynamic and flexible, there is still an assumption that mental health professionals govern and direct the nature of their discourse.

In this research, I am consciously aware that such professional attitudes may misinterpret and misunderstand the dialogue young people engage in. Hence, it is important to be aware that young people may utilise medical terminology or explanations, but the meaning and context of the use of this terminology will not necessarily remain in the dimension of medicalisation. Lay people's explanations and attitudes must be appreciated within the context of who the young people are talking to. It is not a fixed explanation, but one that is dynamic and socially constructed. The Folk Psychiatry Model framework does not offer this level of awareness.

3.2.5 Labelling Theory and stigma model

The stigma theory ideology explains the inferiority that can be endorsed on behaviours that are labelled as a mental illness (Goffman, 1963). Those individuals labelled with a mental illness are distinguished as not quite human. This theory is a key component to consider in the development of lay knowledge about mental illness, as it explains how the inferiority of these individuals can be portrayed and account for representations of danger that they represent.

Scheff’s (1974) labelling theory explains how behaviours labelled as mental illness can trigger negative stereotypes and social rejection (public stigma). Whereas, self-stigma results from loss of self-esteem by the individual with the mental illness due to the internalisation of public stigma. The effect of labelling results in a vicious circle and often a self-fulfilled prophecy of how the individual with a mental illness feels. The creation of this stigma reduces the life chances of the individual, as they are restricted in terms of employment opportunities and engagement within the community.

Stereotypes are collectively held beliefs about social groups, which involve categorising information to quickly generate impressions and expectations of a certain group. These stereotypes can be recalled by individuals but are not necessarily agreed upon or endorsed. Nevertheless, the process of labelling behaviour with terms will undoubtedly create an impression that will form lay knowledge of mental illness.

The possible consequences could be the endorsement of these stereotypes, which could lead to discriminatory attitudes. The belief of an individual being dangerous could make it justifiable to force that individual to enter a hospital or receive medication. The need for segregation and institutionalisation is reaffirmed as an effective way to control these individuals. Consequently, the level of social distancing increases, as there is more need for avoidance and unwillingness to help these individuals.

Link & Phelan (2001, p363) defined this development of mental health stigma as ‘the co-occurrence of its components: labelling, stereotyping, separation, status loss and discrimination’. This model views stigmatisation as a labelling process where an individual has a difference that is socially recognisable. The label produced is then associated with unfavourable characteristics. These characteristics make it possible to distinguish and separate the individual from us and them, enabling that person to be regarded as different from everyone else. This process has now set up the framework to devalue and exclude the individual.

The process of separating us from them, however, will be demonstrated as not a necessary or inevitable progression, as suggested by Link & Phelan (2001). The social construction involved in the dialogue about psychosis will determine whether such a process will occur. Measuring the nature of young people's attitudes is not static, and it is wrong to assume that young people will actively stigmatise if the mental health illness considered is less familiar (Secker et al., 1999).

It is important to increase awareness of the consequences of labels used when discussing specific disorders with the lay person. The level of public stigma recalled needs to be re-evaluated in terms of the extent that it has influenced their own attitudes and knowledge about psychosis. It is sometimes too simple to justify stigma and prejudice when considering the terms used within lay knowledge without understanding the rationale and value placed on the reasoning behind the use of these terms. For example, the extent that mental illness terminology is utilised in everyday conversation can change the meaning and understanding of words within a social context.

3.2.6 Popular discourse of Mental Illness

It is just as important to recognise that the lay person is not as naïve, or a blank book, as was once perceived when considering their knowledge about mental illness. Unfortunately, it appears that the dominance of psychiatry has had an effect of under-valuing lay knowledge without considering the impact of an individual's own personal exposure and experiences of mental illness.

The influence of popular discourse in everyday life clearly illustrates that there is significant awareness of mental illness among the public. Individuals have their own thoughts and feelings about mental illness and have their knowledge shaped within the context of social and cultural constructions. Everyday language, traditions, and institutions in the UK, such as the many 19th century old asylum buildings that exist around our environment, still shape the thinking on the treatment and role that individuals with a mental illness have.

Derogatory expressions such as ‘schizo’ and ‘psycho’ are common terms linked to the condition of psychosis. Media stories have sensationalised terms such as ‘schizophrenia’ and ‘paranoid’ in the public eye, making them familiar colloquial expressions. The context that these terms are used in will alter the meaning attributed to explaining or understanding psychosis-related conditions. It would be unwise to assume that the use of these terms is necessarily derogative with the intention to discriminate. Instead, they have become familiar terms used colloquially within society.

The power and strength of psychiatric discourse will influence how lay people try to interpret abnormal or deviant behaviour. It is common to attribute ADHD with young people’s disturbed behaviour, or to talk about people having a nervous breakdown or being depressed. The diagnostic terms used within these contexts have a different social context with different significance from their clinical origins. The difficulty remains in tapping into and interpreting the different values and meanings that are engaged in popular discourse. It is however important that research considers the value held within the meaning of lay knowledge.

3.2.7 The value of lay knowledge

The value of lay knowledge exists in its ability to challenge the dominance of the medical profession (Popay & Williams, 2006). This challenge in psychiatry justifiably questions the dominance held in medical discourse that often neglects the complexity involved in mental illness (Rogers & Pilgrim, 2014). The level of objectivity of such expert knowledge and truth-claims of scientific knowledge should be questioned when considering lay knowledge (Williams & Pow, 2006). It is inappropriate to discount lay people as ‘driven by ignorance and prejudicial beliefs’ (Rogers & Pilgrim, 2014, p275) when there still remains much dispute between mental health professions when considering the complexity of mental health, as illustrated in section 3.1. This raises the question of how one can justify the premise that professionals hold a singular correct set of knowledge and beliefs that can make someone literate.

The service user movement, for example, from the 1970s has been increasingly acknowledged as a source of expertise when considering the lived experience of mental health. Similarly, lay knowledge is valuable in providing the context for making sense of health behaviour and helping to understand why there may exist a conflict with other experts who disagree (Popay & Williams, 2006). Hence, when considering Jorm et al. (1997)'s definition of MHL, it is important to be cautious about claims that knowledge and beliefs lie in the hands of the professionals. This claim indirectly discounts and assumes that lay people are 'driven by ignorance and prejudicial beliefs' (Rogers & Pilgrim, 2014, p275).

To access lay knowledge, Popay & Williams (2006) have acknowledged that there are significant methodological implications that need to be overcome. No longer can one rely on a positivist framework to obtain such knowledge. Instead, research methods need to be more egalitarian and value/respect the development of stories or narratives as a vehicle for lay knowledge to provide context for making sense of health behaviour.

The changing relationship between experts and the public means that the experts can no longer refuse to listen to people on the ground when in pursuit of truth. There is a loss of trust in experts and a decline in the legitimacy of science (Popay & Williams, 2006). Lay knowledge elevates the privilege of experience and is a political challenge to the status of scientific knowledge and the power of those whom we encourage to trust with such knowledge (Popay & Williams, 2006).

In the same theoretical tradition, the value and position of the young people's voice have become stronger. This lies against the power and dominance that adult professionals have held over young people. The resulting challenge of this notion has enabled the young person to become actively involved in issues that concern their health and educational needs, developing the changing role of the young person.

3.3 Understanding 'Childhood'

The next main challenge in this study was to address and question what position and value young people and children have when understanding their mental health literacy. There was a need to re-evaluate the concept of childhood to challenge notions of children and young people being undervalued, underappreciated, and discounted based on their age.

3.3.1 Developmental Psychology: view of young people and children as ‘becomings’: ‘illiterate’ and ‘vulnerable’

There has been a long history in the UK of young people and children lacking rationality, competence and needing protection. UK social policy has perceived children and young people as potentially dangerous or in danger, assuming that children are vulnerable, need protection and control (Hallett & Prout, 2003; Foley, 2008). Adults are mature, rational, and competent, while children were ‘less than fully human, unfinished or incomplete’ (Jenks, 1996, p. 10). Children and young people were found wanting (Lee, 2001), classified as ‘becomings’, excluded ‘naturally’ as incompetent and incapable and marginalised for protection (Qvortrup, 1994). Childhood became defined as the absence of adulthood (Tisdall, 2012).

This form of discourse continues to reflect the position that MHL viewed the need for young people to have a form of literacy to prevent illiteracy creating a barrier in aiding recognition, management, or prevention of mental illness (Jorm et al., 1997, p. 182). This standpoint remains from an adult professional perspective that young people do not know what is best for them and are reliant on adult guidance and supervision (Watson et al., 2012). Children are portrayed as lacking knowledge of how to prevent mental disorders, the ability to recognise when a disorder is developing, knowledge of help-seeking options and treatments available, knowledge of effective self-help strategies for milder problems, and the first aid skills needed to support others who are developing a mental disorder or are in a mental health crisis (Jorm, 2011). Young people are dependent on adult professionals to impart them with knowledge and understanding about mental health, and it is the adult professional’s responsibility to protect the vulnerability of these young people and improve their emotional wellbeing.

3.3.2 The new sociology of childhood: viewing young people as ‘beings’

Emerging from concerns that young people and the children's voice are not heard properly, in 1990 Allison James and Alan Prout published *Constructing and Reconstructing Childhood.* This started a change in agenda for discussions surrounding the new sociology of childhood. A discussion surrounding the challenges made against understanding the position of young people in society will now follow, which has influenced how this research has positioned itself when conducting research with young people.

James & Prout (1990) argued from the perspective of social constructionism that children and young people should be viewed as 'social actors, as beings in their own right rather than pre-adult becomings' (Holloway and Valentine, 2000: p5). Hence children and young people's social relationships and cultures are worthy of study in their own right, as they construct and determine their own social lives, the lives of those around them, and the lives of the societies in which they live. Children and young people were no longer passive objects or empty vessels in need of adult wisdom (James & Prout, 1990). From this perspective, social constructionism has altered how literacy interventions have been understood from the young person's standing point.

Indeed, it is argued that research should not simply research *on* or *about* childhood as a means of understanding the adult world; but it must be *for* and *with* children geographically, historically and socially situated (Prout, 2005; Cairns, 2001; Christensen and Prout, 2002; Clark and Moss, 2005; Mayall, 2002; Punch, 2002a). Research should consider young people as the *subjects*, rather than *objects*, of research, and engage them as *participants* in the research process, if not as *researchers* in themselves (Cairns, 2001; Kellett et al., 2004). I took the option of engaging young people as *researchers,* re-designing my research methodology in an effort to ensure equal worth was applied to young people's own ways of understanding (detailed discussion in section 4.2).

From the 1990s onwards, the ontological repositioning of the child or young person gradually set up a body of research questioning children and young people about their ordinary experiences, constructed within the structure of their lives (Cocks, 2006). Increased access to funding, for example the ESRC programme

‘5–16: Growing into the Twenty-First Century’ (ESRC, 2001), helped develop research on raising the voice of children and exploring children’s experiences of childhood. The Centre for Research in Education and Educational Technology (CREET) has focused on how a child's right to a research voice can meaningfully and authentically be facilitated. Kerawalla & Webb (2014), for example, explored the use of digital technologies to develop child-friendly virtual learning environments to widen participation in child-led research. The Children’s Research Centre (CRC) training programme has supported (rather than managed) young people to generate knowledge from their insider perspectives (Kellett, 2010). Research by children became the ideal mode of research concerning young people and children’s lived experiences (Tisdall, 2012).

This process enabled an increase in understanding about young people and children as social actors, and the creation of new theoretical and methodological development in cross-disciplinary work (Prout, 2002). Young people and children’s lives became valued and understood on their own experiences, their own interpretations, and meanings.

Hand in hand with the development of the new sociology of childhood has been the development of children’s rights within UK legislation and policy. This development explains the rationale behind increasing young people’s involvement in research.

3.3.3 Children’s Rights in UK policy

The Children Act in 1989 altered the formal position of children and young people within society, emphasizing their welfare. However, the extent that children or young people’s views and opinions are considered still relied on taking the age and understanding of the child into account. Globally, the UN Convention on the Rights of the Child (UNCRC) also supported the academic change in sociological thinking of children as social agents. The UK government in 1991 then ratified the UNCRC to protect young people’s own set of rights, including being listened to and respecting children’s experiences and voices (Articles 12 and 13). A concern in public policy was related to child protection and child abuse, allowing changes to give children and young people the right to be legally represented (separately from parents or the state), to be consulted about decisions and able to complain. In England, this development has continued through Every Child Matters, a Government response to public and state concern about services for children formalised within the Children Act (2004). The Children's Commissioner for England was introduced through the Children Act (2004) to act as an independent voice for children and young people, to champion their interests and bring their concerns and views to the national arena.

The educational needs of young people and children during the New Labour government led to the introduction of the concept of personalisation from a contemporary marketing theory (Leadbeater, 2006; Miliband, 2006). Encouragement centred on increasing the ability for students to co-produce with professionals a solution to their needs, and to produce personalised learning, in which child-centredness, democracy and consumerism in the classroom took increasing priority (Hartley, 2007). After 2010, during the Coalition government, the views of encouraging personalisation of young people and utilising children's views of their educational needs did not gain favour (Bragg, 2014). Instead, there was increased pressure to focus on outcomes measurement and accountability (Solomon & Lewin, 2016). Perhaps representing the tensions that exist between democracy and consumerism.

Nevertheless, the legal position of young people has promoted the opportunity for research to engage young people in research. Together with the theoretical stance taken by James & Prout (1990), there has been increasing justification and funding available for research to specifically increase their efforts to further young people's involvement in research. An overview of this development will now follow

3.3.4 Critique of the 'new' sociology of childhood: Young people and children still 'becoming' and 'being'

More recently, there has also been a counter challenge against the attractiveness of the emancipatory and democratic thinking behind the new sociology of childhood. It has been argued that both adults and children must be seen as both becomings and beings. If children are just beings in their own right there is a risk that we falsely see young people and children as autonomous and independent. In fact, all humans are part of multiple interdependencies (Prout, 2011). No humans are experts but are emergent becomings, unfinished subjects with potential. Hence developmental psychology, once dismissed as undermining the rights of children and young people, has held relevance in studying changes in transition within different socio-economic and cultural contexts (Woodhead, 2009). Acknowledging the importance of cultural and social learning that takes place in the young person's world (Vygotsky, 1978).

The new sociology of childhood has been criticised as trying too hard to portray children and young people as competent social actors to counteract traditional views of children as passive dependents. The result has been neglect in considering young people and children in multiple contexts, examining the meaning and relationships they form within these contexts. For example, the young person and children's position within the family context has ignored the position and relationship of young people as 'familiar objects' (Holt, 2011).

Further attempts to challenge stereotypical images of children and young people as the product of adult abuse, within adult constructed concepts of "child labourer," "child bride" or "child prostitute," the "child soldier", have diverted attention from the real problems that lie behind these childhood experiences (Rosen, 2007). Further investigation is needed how a dependant, exploited, and powerless relationship has developed between young people and adults. It is not a one-sided relationship that is involved when viewing it from an adult or a child perspective.

Hence, this research takes on board this counter argument and has realised the need to consider the different social circumstances involved which may shape how young people communicate their views differently (Prout, 2011; Holt, 2011; Rosen, 2007). A central aim of this study is to address this issue by exploring the diverse ways in which young people interact with adults, compared with their young peers. Hence, my ontological and epistemological position has been to take a social constructionist approach in my research methods to explore the rich social context involved within young people's dialogue about psychosis. This has helped me understand and appreciate that the young person's world is shaped within an adult's world.

3.3.5 How has the ‘new’ sociology of childhood challenged conceptualisations of young people’s health needs?

This section explores a choice of literature on young people’s views about wider health concerns and illustrates some of the tensions between adult and young people’s views about their health-related needs. Due to the lack of research literature that has considered the social construction of mental health among young people, this section will explore some notable examples that illustrate how other researchers have challenged the perceived adult professional perspective of young people’s health needs. This discussion is important in terms of setting up a substantial rationale to problematise understanding young people’s needs for mental health literacy.

Some writers have argued that an adult-focused deficit framework has often been applied when understanding young people’s risky behaviours in health (Morgan & Ziglio 2007). The understanding of the meanings that young people assign to their own health behaviours does not always supply insight as to why young people do not always act in ways that adults approve of. The adult-focused deficit framework simply views youth lifestyles as problematic. Adult-led agendas should not ignore young people’s experiences of their health needs as interpreted within social, economic, and political contexts (James et al., 1998).

Brooks & Magnusson (2006) explored young people’s views about what would make an effective PE curriculum. The study explored thirty-one, self-identified, formerly PE adverse students aged 14-15 years and rejected the simplistic view that inactivity is the result of problematic lifestyles. These lifestyle choices included computer game playing. Brooks & Magnusson (2006), however, were able to explore how these PE adverse students perceived the school as trying to ‘exert control over their bodies in ways that the participants reported finding stressful’ (Brooks & Magnusson, 2007, p877). The overuse of showers, inflexible adherence to PE uniform and lack of choice over activities were examples of how PE became stressful. Emphasis on competitive success physically marginalised individuals unable to occupy positions of high achievement.

Understanding the social meanings that PE held for these young people enabled Brooks & Magnusson (2007) to implement changes in the PE curriculum to increase PE adverse students' levels of motivation and confidence to feel more valued and enjoy their PE activities. A similar approach when considering young people's health needs could open an alternative dialogue not previously appreciated as relevant. At the same time, one must acknowledge that suggestions made by the young people may conflict with the agenda set by adults. These included, in the context of the PE curriculum, the use of showers for hygiene purposes, the benefits of learning specific sports and the need to follow a uniform policy.

It is important to understand how possible adult-led agendas could run counter to young people's own beliefs and experiences. Wills (2005) and Wills et al. (2006) conducted a diet and obesity study in three schools in Scotland with participants aged 13–15 years (eighteen boys and eighteen girls). Results contradicted beliefs that obese young people disliked their body image. The obese young people said they liked their bodies, or parts of their body, and were satisfied with their overall size or shape (Wills et al. 2006). Most did not view themselves as being over-weight and conceptualised their body shape with the shape and size of extended family members (Wills et al. 2006). Instead, participants felt weight loss among their peers was not needed and were worried that peers should not feel pressured to lose weight. The risk of developing an eating disorder because of this pressure was more concerning than the risk of being obese.

Wills (2005) and Wills et al. (2006) argued that young people's disengagement with public health discourses about obesity was not because young people are ignorant of the facts, but because the conceptualisation of their body fits in with the bodies of their peers and family and they do not feel ill (Wills, 2005; Wills et al., 2006). Understanding the social meaning of obesity is therefore important in relation to developing public health outcomes. The application of these views may explain the reasons why young people may disengage in MHL strategies if the interventions are alien or irrelevant to young people's needs.

All of these studies (Brooks & Magnusson, 2007; Wills, 2005, Wills et al., 2006) demonstrate that young people place emotional wellbeing high on the agenda in terms of their health needs. This highlights that the focus in health education is often on physical health (in these cases, improving exercise and tackling obesity) and has neglected their emotional wellbeing needs.

In Coombes et al.'s (2013) study eight focus groups in five secondary schools with pupils in year 10 (aged 13–14) explored the views of young people about their emotional wellbeing in the context of secondary education in the UK. Coombes et al. (2013) suggested that young people felt that certain mental health topics were neglected in the Emotional Health and Wellbeing (EHWB) curriculum, especially in relation to self-harm and anorexia. There is a need for further discussion about what specific topics should be addressed in young people's MHL in order to not assume that certain topics are irrelevant to young people's needs. The focus Coombes et al. (2013) chose regarding EHWB was also flawed to assume that mental illness was not relevant for young people.

Similar to Brooks & Magnusson (2007), Coombes et al.'s (2013) study demonstrated that young people were able to provide insight into how to improve the teaching of the EHWB curriculum that was more relevant to their learning needs. Factors mentioned were increasing the enthusiasm and creativity of the teacher providing EHWB and talking to friends to increase the levels of empathy when discussing EHWB issues. It is inappropriate to impose teaching methods on young people without taking consideration of their relevance for the young person.

There are also parallels with research conducted that has explored the implementation of Sex Education. Ellis, Pagarani & Fauth (2009) explored young people's views of sex and relationship education provision in FE colleges in six focus groups of 6-8 young people in four FE colleges based in London (except for one college). Young people in this study felt that sex education was framed negatively to teach them not to have sex, emphasising sexually transmitted diseases and pregnancy. The emotional or positive aspects of sex were neglected, and there was a lack of acceptance that young people may choose to have sex at younger ages. Young people felt sex education should inform them more about the events leading to sex or alternatives such as foreplay, and that there should be more inclusion and provision for LGBT students. There was an overall general feeling that teachers were inadequately trained to deliver SRE. The young people suggested exploring the lived experience of real couples and real-life stories, as well as a forum for peer support to enable young people to discuss issues.

The RIPPLE study, reported by Stephenson et al. (2008), conducted a cluster (school) randomised trial to assess the effectiveness of one form of school-based peer-led sex education in reducing unintended teenage pregnancy. Results showed that peer-led sex education was popular with young people, and may have led to fewer teenage births, but the results of the trial showed that it was not associated with changes in teenage abortions.

It could be argued that if too much focus is placed on satisfying young people’s conceptualisations of their health needs, we may neglect deserved attention to the problems that adults and professionals view as important for young people. For example, in Wills (2005) and Wills et al., (2006), acceptance that obese young people had no problem with their body image does not make these young people less at risk of associated health problems related to obesity. Similarly, the importance of learning about sexual pleasure in Ellis, Pagarani & Fauth (2009) does not supply any discouragement to prevent teenage pregnancy.

3.4 Implication of theoretical challenges

From this theoretical discussion, it has become clearer that the direction needed to evaluate young people’s psychosis literacy should encompass an overarching conceptual framework of social constructionism. Social constructionism rejects positivist claims of reality and values the need for an exploration of multiple interpretations of perceived reality developed through different social dialogues (Crotty, 1998). The hope is to shine a new light on how young people socially construct their understanding and meaning of psychosis within different social interactions.

Exposing the complexity attached to the meaning of psychiatric diagnostic terminology has illustrated the need to be aware of how meaning attached to this terminology is not as straightforward as previously assumed. The value of adopting social constructionist principles will allow young people’s experiential knowledge to be understood as worthy in its own right through different social contexts, and not simply caged within a professional discourse (Lupton, 1994; 2000; 2012). Previously discredited knowledge, understanding, and attitudes held by young people will achieve equal worth, value, and status alongside that of the professional. The opportunity to interpret and understand young people's knowledge and understanding away from the dominant medical discourse will prevent assumptions being made against young people's illiterate and stigmatising attitudes of mental health (Burr, 2015).

The value attached to lay knowledge, as well as a re-appraisal of the new sociology of childhood, have therefore all justified the need to take a different methodological approach to capture the young person's voice. Social constructionism gives equal worth to the different ways young people create their understanding and meanings as historic and cultural artefacts (Burr, 2015). It is time more value and time is devoted within research to appreciate how young people's dialogue will alter depending on the social setting they are engaged in. This has then led to the use of a participatory peer research method compared with a traditional AR-led focus group methodological approach. The next chapter on methodology will discuss in further detail the importance of applying this framework in the application of this research.

Chapter 4: Methodology

4.1 Introduction

As discussed above, a social constructionist framework was decided as the right approach to challenge key concepts named in this research. This has fundamentally influenced the choice of using peer research methodology to obtain access to different influences within young people's dialogue. This will involve considering the different demand characteristics of being interviewed by your peers compared with the data collected by the AR. The sampling, data collection and data analysis stages of this research will then be reflected upon, including ethical considerations met, concluding with an overview of the benefits and challenges achieved in the methods used in this research.

4.2 Rationale for using peer research methodology

Peer research involves using researchers who are the peers of the participants of the study. Peers can be defined as sharing the same age, status, ability, background or status, in this research the peers were fellow classroom students in the same age category (Nairn & Smith, 2003). Peer research has developed from the traditions of participatory and empowerment research; acknowledging, when working with young people in particular, the fundamental need to listen and increase the young people's voice to understand their health educational needs (Schäfer & Yarwood, 2008). Increasing the young people's involvement in the research process in a bottom-up approach, creating democratic participation and social justice for young people to influence the research process.

There is increased expectation that young people will personally gain from the research findings, and that changes will result from the research (Kirby, 1999). Research is conducted *with* young people, not *on* young people. Challenging societal views about young people's incompetence, ignorance, immaturity, and irresponsibility (Mayall, 2000). Young people are social agents, treated as experts in their own lives with a right to be heard on matters that affect their lives (Morrow & Richards, 1996; Mayall, 2000).

Peer research avoids the traditional hierarchical relationship between ARs and young participants. Within this relationship the good participant role shapes how young people may construct their responses for an adult audience to comply with an authority figure (Nichols & Maner, 2008; Bjorklund et al., 2000). This could include the possibility of participants conforming to questions asked, even if they privately disagree, to appear good in the eyes of the researchers (Nichols & Maner, 2008). The apprehensive participant role also involves participants reacting in a socially desirable manner and being wary of what they disclose because of concerns how the researcher may interpret their views (Barabasz & Barabasz, 1992). Personal views are avoided due to fear that an outsider would misinterpret or misjudge their responses (Barabasz & Barabasz, 1992; Warren, 2000).

One criticism laid against the influence of ARs on young people is the imbalance of power in the relationship between adults and young people. Fear and caution can influence what young people can discuss during research projects, as proven during attempts to obtain views of informing decision-making with looked after children (Cunningham & Diversi, 2012; Moore, Saunders & McArther, 2011; Kilpatrick et al., 2007; Ward et al., 2005; Curtis et al., 2004; Shier, 2001). This level of fear has even resulted in young people being unwilling to criticise or disagree with the research topics discussed (Fine & Sandstrom, 1998). ARs have been accused of picking and choosing specific young people’s views more seriously than others, only listening to responses that fit in with their own views (Hill, 2006).

The outsider relationship of the AR will influence the meaning constructed between researcher and participant (Gubrium & Holstein, 1997). This includes, for example, how young people may become over-reliant on the AR, viewing the researcher as an expert on the topic and expected to control the direction of the research (Bloor et al., 2001). In this study, this relationship may occur as the young people did know my professional background. Therefore, young people’s responses may become shaped within a context determined by the influence of the AR.

It is therefore hoped that PRs will increase confidence in the participants' responses not to 'sugar coat their answers' but gain greater control to talk openly and honestly with personal disclosure when discussing sensitive topics (Kirby, 1999; Burns & Schubotz, 2009; Kilpatrick et al., 2007; Schäfer & Yarwood, 2008). Peer research could then provide the chance to challenge issues, and put forward reasons and arguments with more room for multiple interpretations (Grundy, 1996). This influence could allow young people to identify and prioritise research issues that ARs were not aware of, and would not have previously considered (Smith et al., 2002).

Parallels can be drawn on the benefits of involving peer educators for sex education. Forrest, Strange & Oakley (2002) found that 4754 students from 27 mixed-sex English state schools involved in peer-led sex education felt peer educators related well to their peers, were perceived as credible and made students feel relaxed during 'fun' activities, appreciating the fact that they were not being lectured to. Lupton & Tulloch (1996) and Buston et al. (2001) similarly expressed young people felt that their confidentiality would not be compromised and that they did not feel looked down upon. Peer educators were more tolerant of the language used to describe sexual behaviour and the level of background noise generated by small group work and conversations between students. Peer educators also allowed more time for participants to clarify their thoughts or ask supplementary questions, which they felt was not possible with teachers.

In Grundy's (1996) study, participants in a peer-led research project felt that they had more of an equal chance to challenge issues and put forward multiple interpretations. The peer-led semi-structured nature of the interview format used in Kilpatrick et al.'s (2007) study created a high degree of control for participants to feel free to talk openly and honestly, allowing rapport and trust to develop to increase personal disclosure. PRs developing their own research activities results in more suitable, relevant, and engaging methods to open discussion about sensitive topics (Smith et al., 2002). This influence allows young people to identify and prioritise research issues that ARs were not aware of and would not have previously considered (Smith et al., 2002).

These advantages have not been universally agreed upon. There still exists the issue of a power imbalance between the PR and the participants; peers collecting data are in a powerful position vis-à-vis other young people (Kirby, 1999). It is usually the more energetic and outgoing confident young people that volunteer to become involved in research projects. These individuals are more likely to be from middle-class backgrounds and may have less in common with their peers, many of whom will have a more passive attitude towards involvement in research (Kirby, Laws & Pettitt, 2004). If friendship groups are drawn on when recruiting PRs, the dynamics involved can have an impact on how participants interact with each other during the data collection stage (Kirby, Laws & Pettitt, 2004).

Lack of experience and authority in PRs could create the possibility of PRs being unable to distance themselves sufficiently from the research topic to allow open discussion (Jones, 2004). For example, Allen (2009) commented that some participants in peer-led educational sessions said they avoided peer educators because ‘They’d probably like tell their friends and all’. There is always the chance that classroom management is not effectively maintained. Forrest, Strange & Oakley (2002) commented that lack of engagement for girls was caused by peer educators being perceived as having less authority than teachers, which resulted in boys teasing, denigrating and bullying girls. In this research, these factors may be influential in the classroom setting. There is a danger that only the articulate privileged young person’s voice is heard, as argued during the ‘Make Your Mark’ campaign (Bland & Atweh, 2007).

Although peer research methodology is widely used in fields such as sex education, there is a lack of research on its utility in the context of mental health awareness interventions. The application of peer research methodology within this field could potentially create the opportunity for more open dialogue between young people and create a different meaning and understanding related to the social construction of young people’s understanding and knowledge about psychosis.

There is, however, little systematic, comparative work on the differences in data collected by ARs with that collected by PRs. This research attempts to bridge this knowledge gap by directly comparing these two sets of data. Such comparison in this research hopes to increase appraisal and understanding of whether and how peer research methods enhance the value of data collected. This form of evaluation will focus on questioning the potential benefits of peer research methods as having the ability to capture more private than publicly acceptable views and opinions of young people in direct comparison to AR-led focus groups.

The aim of this comparison is not to be critical of demand characteristics as a form of contamination, but to value and explore how meaning is generated and contextualised through different social interactions (Monahan & Fisher, 2010). Utilising different methodologies to explore different forms of social interaction can increase access to alternative rich and holistic accounts. Peer research methodology is one method of such triangulation used in this research to open access to young people's social interaction.

I will now turn my attention to explain in more practical terms how my research methods were carried out, and what challenges existed in the process. To do this, an overview of the research design will first be set out.

4.3 Overview of research design

As an introduction to the design of my research methodology, I will set out an overview of how the research was divided into three separate phases:

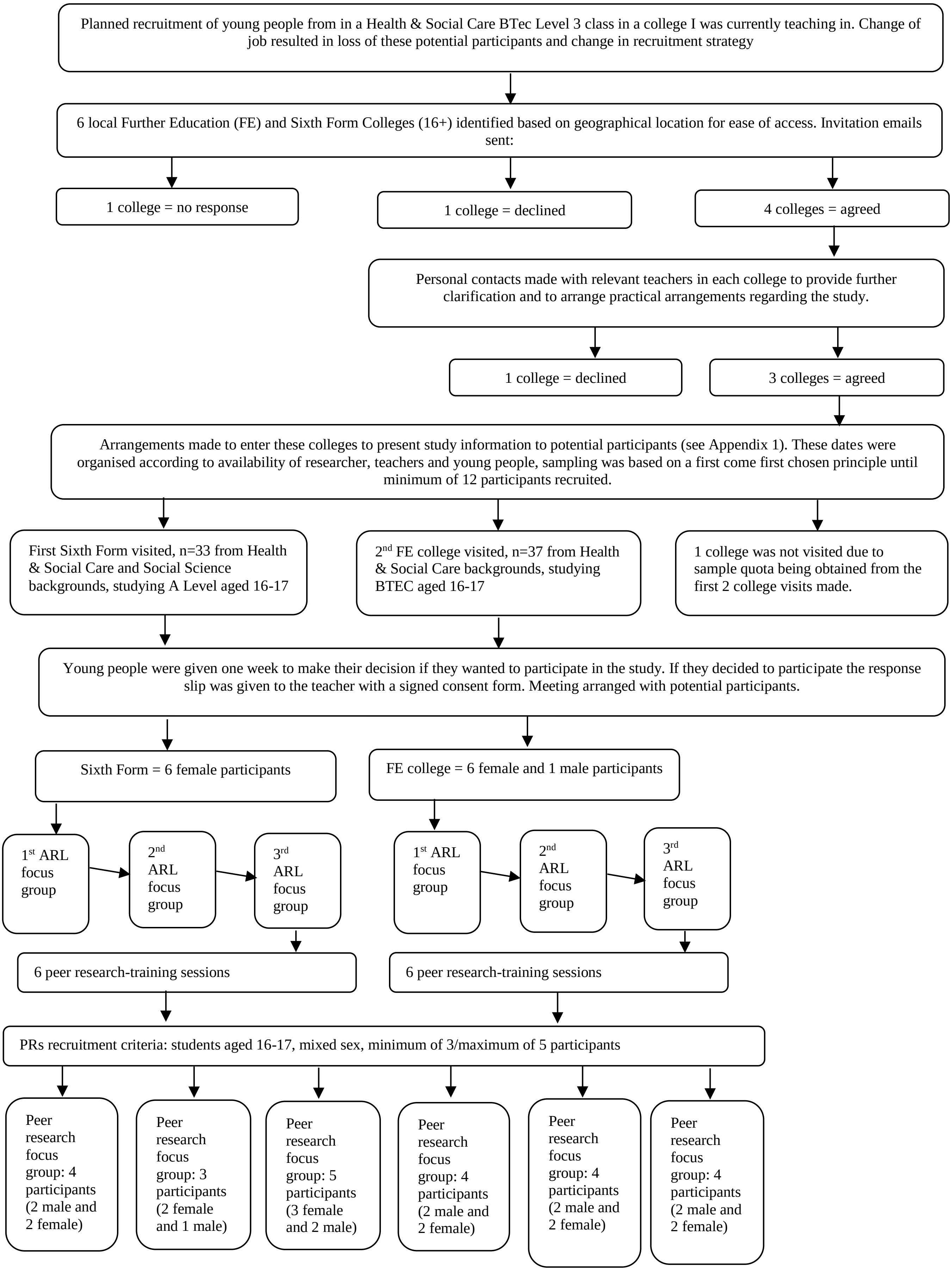
- **Phase 1** involved the principle AR (myself) recruiting young people from two separate colleges (one Further Education and one Sixth Form college). Once recruitment was completed, three one-hour focus group sessions were conducted over a period of three weeks (one every week) in each college (six focus groups conducted in total). Another colleague was in attendance during these focus group sessions for note taking purposes. Each session was divided into three separate themes:
- Session 1: Exploration of young people's existing knowledge of psychosis.
- Session 2: Exploration of young people's views of different teaching methods that could be used to teach psychosis literacy.
- Session 3: Exploration of young people's ideas about how to formulate an appropriate psychosis literacy programme for young people.

- **Phase 2** of the study involved engaging the young participants in six sessions of peer research training (within each college) to prepare the young participants as secure, ethical, and competent PRs before conducting a mini-study on this topic amongst their contemporaries. The PRs practised and discussed skills necessary to engage their peers in discussion and created their own resources and script sheet to direct their semi-structured focus group questions (see Appendix 9).

- **Phase 3** of the study began once the PRs showed to the adult researcher that they were ready to start their focus group sessions. The PRs worked in pairs to recruit friendship groups to a focus group session organised by them in available classrooms within their college, at a time that was most convenient for all to take part. This second round of recruitment enabled a wider group of young people to be recruited without the usual limitations placed by adult gatekeepers (Powell & Smith, 2009).

These phases of the study have been pictorially represented using a flow diagram (Figure 4) to illustrate specifically how the sampling of the study was conducted. This will indicate to the reader how choices were made during the research process and why the research was conducted in the manner it was. Further detail of each phase will then follow in the succeeding sections.

Figure 4: Flow diagram of research sampling/recruitment



4.4 Phase 1

This project received approval from Teesside University's School of Health & Social Care Research Governance and Ethics Committee on the 5th October 2012 (see Appendix 7). Please refer to Appendix 6 for detailed ethical approval documentation. Once approval was obtained, Phase 1 was started. The main achievement was to succeed in the recruitment of willing young people aged 16-17 within further education institutions to engage in ARFGS and become PRs. The sampling framework used to achieve this stage is set out below to illustrate some of the difficulties involved when recruiting.

4.4.1 Sampling framework

Initially, participants were to be recruited in the further education college I was teaching in. However, once I had ethical approval and I started the recruitment of participants, I was no longer working in this college and had a new job away from Further Education. I was therefore no longer one of the gatekeepers to participants of the study and did not have access to potential participants for my study. The result of this change of circumstances was that I had to now rely on my ex-work colleagues to be supportive gatekeepers to recruit potential participants. Unfortunately, the response was not positive, as they did not perceive the potential benefits of their students being involved in this study.

The decision was made not to rely on this source of recruitment. I was annoyed and apprehensive about this decision. This was because I had already discussed my proposals with the young people, they had already agreed to participate and I could see great learning outcomes for the students to be involved in such an opportunity, which could have assisted them in their research module. I felt that I had let the students down and had to explain to the students that, unfortunately, they would not be able to participate. This experience clearly showed the power of gatekeepers over young people's decision making.

On a more positive note, this change of circumstances meant that I was no longer limited to recruiting young people from the college environment I had previously been working in. The recruitment of participants could be widened to involve young people who did not know me in a teaching position. This was an advantage because it is likely that my position as the participants' teacher could have influenced the young people's responses. This influence could include young people not wanting to appear less knowledgeable or express stigmatising attitudes than if responses were provided to an AR they did not personally know. This influence would include their decision to participate in the study or the responses that they would have provided during the study. This decision also released me from having to travel extensively to conduct the fieldwork, giving me the opportunity to recruit in a geographically convenient area for ease of access.

Six potential colleges were located within a radius of 16 miles from where I lived. Contact with these colleges was made via email with a letter attached detailing proposals about the nature of the research being conducted and what requirements were expected from the young people who would participate in the research (see Appendix 6). One college declined to participate as they felt that the research project would place too many demands on their students. One college did not respond and was not pursued further due to the other four colleges expressing interest to take part.

The four colleges that expressed interest in participating in the research were visited in turn, as I was provided with contact details of the individual teachers who taught health & social care or social science-related subjects that related to the topic of my research. My visit involved discussing the nature of the research and the practicalities of the research for the college and myself. I also explained that my sampling was based on a first-come-first-served basis, involving a minimum sampling quota of 12.

During these visits, one college decided once hearing the details of the research that it would be inappropriate to ask their students to be involved as the students were at that time already engaged in project work which needed to be handed in. I then approached the remaining 3 colleges, whose teachers were positive about the prospect of their students participating in the research study.

The teachers of these colleges subsequently allowed me to organise meetings with potential participants to discuss the context of my research proposal and offer the chance to participate. The students involved in these meetings were all studying health & social care or social science-related subjects, as the teachers considered that these students would be the most appropriate to be involved in this research topic. These subsequent meetings with the students (total = 67) were held in college classrooms and were arranged by the college teacher with both staff and students in attendance. Information was provided in a PowerPoint presentation, with question being asked throughout the presentation (see Appendix 1). Written information was provided to the young people, as well as a tear-off slip to be completed and returned if they decided to take part (See Appendix 6).

Once I had conducted these meetings with two of the colleges, my sampling quota of 12 had already been met, recruiting 6 participants from the first college (named as S college) and 7 participants from the last college (named as D college). I then informed the third college that their participation was no longer needed, but that I would contact them if circumstances changed in my study. Considering the number and level of interest expressed by the young people present during these meetings, I was surprised by the small number of volunteers. The subject teachers explained the reason for this was because students were unable to volunteer either because of prior commitments or the timing of the research sessions. It was also through discussion with the teachers that potential participants were recommended whether they should participate or not. One conversation witnessed involved a teacher telling a student they could not participate because of the level of work they needed to catch up on.

It was expected that the participants’ health & social care/social science background interests would influence how they responded to discussions about the topic of psychosis. The influence expected was the degree of interest and existing knowledge they would have prior to the focus group sessions.

In targeting this group of students, there was also an expectation that more female students would be involved. This is because there is a statistically greater proportion of females studying health and social care than males, as illustrated in the graph below (DfE, 2012):

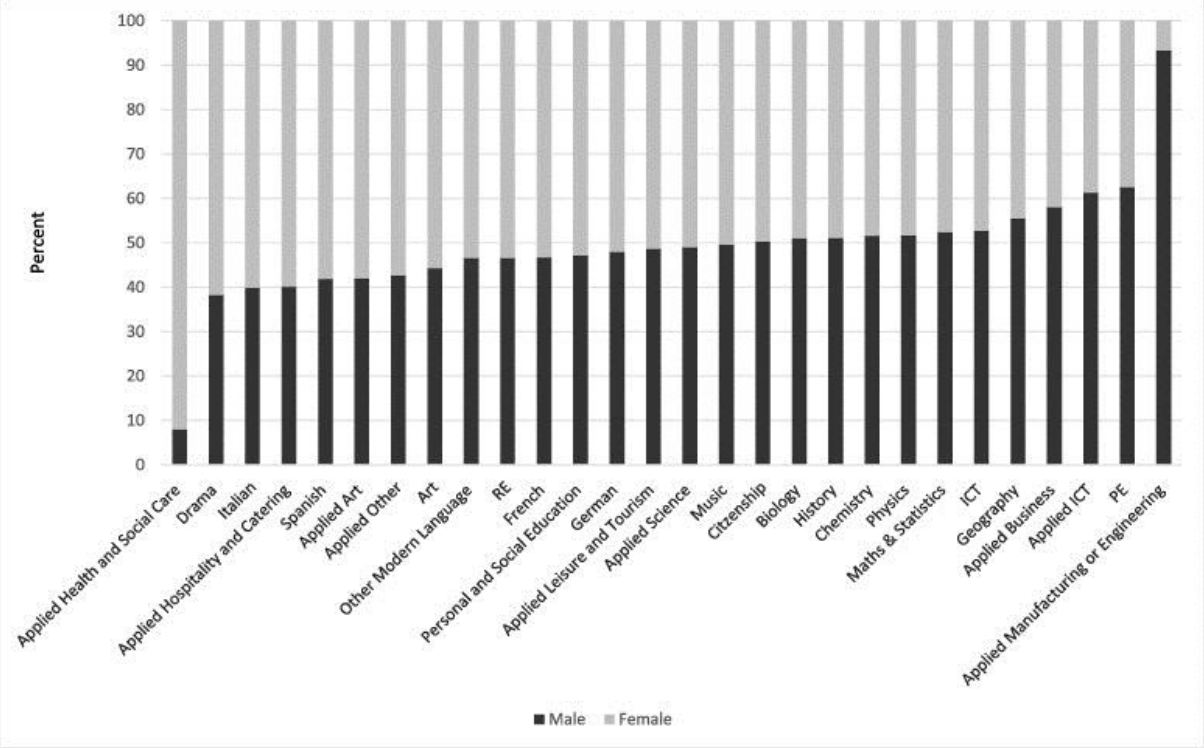


Figure 5: Gender difference in GCSE subjects: Source DfE (2012)

In fact, this expectation was true, as recruitment resulted in only one male participant recruited from the 13 students involved.

It is also highly likely that the young people who volunteered will have higher GCSEs due to their willingness to engage in extracurricular research, a common observation when recruiting peer educators (Forrest, Strange & Oakley, 2002). This is influenced further by the college teacher’s decision to prevent participation for those students considered as needing extra support in their studies. However, no information about the PR’s academic ability was collated, so no firm conclusions can be drawn from this.

When I presented verbal and written information about the research in both these colleges, it is important to note that I disclosed to potential participants my professional background (see Appendix 1). The rationale for this disclosure was based on developing mutual trust with the young people so that they understood why I was conducting this research and the choice of the topic chosen. I acknowledge that this will potentially influence the participant role, but some influence would have still occurred in terms of my position as an AR. Hence, morally I felt more comfortable to explain the reason for conducting this research. I could not expect the young people to confide in me if I was unable to confide in them. A co-operative working relationship was fundamental in the recruitment stage.

I tried to avoid placing pressure on the young people when they made their decision to participate in this research. This was, ironically, helped by the failure of my plan to recruit participants from the college I was working in, as even though this method would have probably improved my level of recruitment, there would have been a potential risk that the young people could have felt pressurised into the research to please their teacher.

I was, however, aware that this form of pressure could still have applied in the two colleges chosen within the sample. This is because the college teachers were in approval for their students to take part and were present when I delivered my presentation to the young people. The danger could be that young people were only participating to please their teacher that they are involved in an extra-curricular activity that supports their academic standing to apply to university, which may be relevant as the young people did know my position as a Lecturer at Northumbria University. It was therefore important that participants were aware that no form of favouritism was given to those who participated in the study. The young people were also given a week to think about their decision about participating and did not have to contact the researcher directly but vis an opt-in method via a self-return tear-off slip indicating whether or not they want to participate. The problem with such a method is, however, that it enhances the risk of excluding those who are shy and less confident (Schäfer & Yarwood, 2008).

In terms of gaining informed consent from the young people, since all participants were aged 16-17, it was decided by the AR, through discussions with the supervisory team and the University’s ethics board, that it was deemed not necessary to request parental consent. This is even though some guidance, such as the General Medical Council (GMC), stipulates that even if the young person (aged 0-18) is able to consent for themselves, you should still consider involving their parents. However, the National Children’s Bureau (2011) research guidelines make it clear that young people aged over 16 do not need parental consent unless the research was conducted in the family home, the young person is vulnerable or the topic discussed is sensitive, troubling or for looked after young people (social worker's consent must be obtained) (Shaw, Brady & Davey, 2011).

The rationale of peer research methodology supports the decision in not requesting parental consent. This is because the primary aim is to protect the rights of young people to participate and express their opinions (Beazley et al., 2011). Gaining parental consent could potentially become a barrier in terms of promoting young people's rights as it gives the impression that participants do not have the ability to consent by their own right. It is important in this research that participants felt that they are trusted to be able to decide to participate in the research by their own free will, recognising their agency and citizenship (Tisdall, 2008). This is even though there is a possibility that the topic discussed could be particularly distressing for them, or they may have been looked after young people (this information was not known).

There was no doubt during the research that the young people recruited were able to give informed consent, and when the PRs recruited their participants they set their inclusion criterion based on the ability to give informed consent. The assessment of informed consent was conducted throughout the focus group sessions, by ensuring that all young people were entirely free to volunteer to participate (no feeling of being pressurised) and were given at least a week to make their decision, with full information about the research. Question and answer sessions assessed the participants' ability to paraphrase what the research was about and what their involvement would include. This was formally evidenced in a signed informed consent being obtained from all young people involved in the research (see Appendix 6).

I was, however, aware that the participants' involvement in a discussion about psychosis could potentially be upsetting and distressing, especially since it was unknown whether participants had a relative or family member suffering from psychosis, or if they themselves have or were experiencing symptoms of psychosis. The measure put in place to reduce such distress was to ensure that participants were comfortable and fully aware prior to participating that they would be engaged in discussing sensitive issues about psychosis. This involved making participants aware that they could withdraw from the research at any time and did not feel pressurised to continue engaging in these discussions. The AR and PRs established ground rules prior to the focus group sessions regarding the need to respect each other's opinions and made expectations clear that any deliberately offensive comments were unwelcome.

If any young people did become upset about any discussion that occurred during the focus group sessions, it was important that the primary researcher was contactable. As a qualified mental health nurse with professional experience of providing mental health support to young people, I was well positioned to support these young people and direct them to relevant external and internal agencies if required. Misinformed views, opinions and attitudes associated with mental health were intentionally not challenged by the researchers during the focus group. It was therefore important that at the end of each focus group session participants were directed to relevant agencies, such as Young Minds, if they felt they needed more information about psychosis.

There was also the potential for young people to disclose information about themselves or others. This was despite stipulating at the start of the research that this was not the purpose of the research and participants were warned not to discuss matters of a revealing personal nature or to talk about other individuals by name. A ground-rule-setting opening activity ensured that the young people understood the reason for not disclosing such information and, if they did, what the possible consequences would be. It was explained that if young people did raise any issues that, in the view of the researcher, seem likely to lead the young person into harm or danger, the researcher will report the matter to the teacher responsible for their pastoral care. These issues were ironed out by the PRs during the peer research training sessions, and part of the training involved the AR supporting the PRs to devise information for participants explaining the nature of the research and the ground rules on confidentiality, which were used as reminders to participants throughout the sessions.

Permission from participants was obtained for the focus group sessions to be audio-recoded. There were no concerns expressed by the young people in terms of being audio-recorded. An assurance was given that the data would be stored securely on a password-encrypted machine at the researcher's own home, to which only the researcher and professional transcriber had access to, and files would be deleted after use. These anonymised transcripts were entered into NVivo in order to manage the data and pseudonyms of their own choosing were used. The list connecting the real names with the pseudonyms used are held separately and securely on the researcher’s password protected Northumbria University server (U-Drive).

It is also important to note that certain young people were excluded from participating in this research due to constraints in the college’s timetabling system. Only a certain period for the research to take place was allocated by the college teachers, which reduced the degree of flexibility warranted to improve participation. This placed more commitment on behalf of the participants, as in both colleges there was a requirement that the research focus group sessions did not affect lesson time. In one college this was a Wednesday afternoon, which was dedicated to Union and Sports activities, and in the other college a late afternoon period was chosen (considering accommodation for student bus travel).

The level of commitment required a significant amount of time to be invested by the young people who participated. This was one of the main potential barriers to recruitment. The need for this level of commitment was explained to the young people before they decided to participate. It was not as simple as turning up for one focus group but involved a three-phase approach. I appreciated and did not take for granted young people’s level of dedication or underestimate the commitment involved in this study.

These young people were giving up their time to participate in the research, which would have constrained their social, personal and academic commitments. Examples experienced included the need for young people to catch public transport to get home (the free college bus) and the fact that in one session two students had to leave earlier due to medical/dentist appointments. This meant that it was important to be flexible to cater for young people’s different needs, respecting and asking participants when and where it was most convenient for the sessions to be conducted. In practice, this flexibility was unrealistic for the AR, as there were numerous limits placed by the individual college’s commitments.

This influenced my decision to use vouchers and certificates at the end of the study to acknowledge the PRs for their time, commitment and ability/skills proven throughout the research process. It was decided that it would be unethical if vouchers were not provided, as the use of vouchers attempts to equalise the uneven power relationship between the AR and young people, as justified in the feminist tradition of research (Thompson, 1996; Head, 2009). From young people’s comments when receiving the high street vouchers, the vouchers appeared well received, but interestingly the provision of certificates was more appreciated. It was at the young people’s request that certificates were provided, as they wanted proof that that had participated in a research study and had obtained the skills as a PR which they could refer to on their CV:

Image 1: Certificate of Achievement

CERTIFICATE OF ACHIEVEMENT

is hereby recognized for participating in a PhD Research study sponsored by Teesside University involving:

- Three focus group sessions exploring ‘Psychosis Literacy’
- Five research training sessions to become a ‘Peer Researcher’
- Conducted a research focus group session to generate qualitative data

Teesside University

Teesside University is sponsoring this project for the purposes of research governance

SIGNED: Andrew Ramtohul (PhD Researcher)
BA BSc PGCE RNMH MA

DATE: March 19, 2013

As a gesture of thanks to the young people for their commitment, refreshments were provided after each focus group, although uptake was disappointing. My initial thoughts why this might have happened was because the snacks provided were not suitable, so the young people were asked what snacks they would prefer. However, still this did not seem to have any effect. The more likely explanation for this was because of the timing of the focus group sessions, as the young people did not want to stay longer in college afterwards to eat the snacks. Instead what proved to be more appreciated was the provision of High Street vouchers and certificates to recognise what skills the PRs had obtained from their participation.

The use of payment incentives in research is problematic. Head (2009) has highlighted the methodological, ethical, and practical issues raised by introducing payment incentives in qualitative research. One needs to reflect upon these issues and not hide them in the margins of research. The impact of using on influencing vulnerable individuals on low incomes may create the feeling of being coerced to participate in if the reward is too high to refuse (Goodman et al., 2004). Young people could be financially disadvantaged to the extent that the prospect of gaining high street vouchers could compromise the principle of free and informed consent in the study. Head (2009) also noted the influence of the researcher informing participants that incentives are involved and when the incentive would be given. In this research study, the PRs were informed at the start of recruitment and would be given the vouchers once all stages of the study were conducted. This has an implication in terms of encouraging recruitment and preventing drop out, both of which are ethically problematic when respecting young people's level of consent. However, it was important to emphasise the fact that young people were given vouchers for their participation and not for what they said in the research. This is because there have been worries that the implication of paying participants would lead to participants telling the researchers what they want to hear (McKeganey, 2001).

Once recruitment was completed, the next stage was to engage the young people in three separate one-hour AR-led focus group sessions over a period of 3 weeks. The experience of conducting these focus group sessions will now be explored in my next section on data collection.

4.4.2 Data collection: ARFGS

The intention of this section is to provide an explanation to the reader of the nature of the decision-making and justification involved when the AR conducted their focus group sessions.

The influence of young people being interviewed by an AR, as discussed previously, is thought to have a considerable influence on the type of responses young people provide. It is this influence that provides opportunity to analyse the extent to which young people conform to a medical discourse about mental health (Bloor et al, 2001). This is an important consideration to understand how young people may engage in dialogue about mental health within a school environment. The influence of the decisions made by the AR during the focus groups is important to understand how these decisions will influence the young people's responses.

One of the main influences the AR possessed was the type of questions chosen during the focus group sessions. These questions were built around the main objectives for conducting the research, to find out what young people's knowledge and understanding of psychosis was and what type of education young people thought was most appropriate for their needs. The degree of flexibility and openness of the questions asked was an important feature that I wanted to provide in order that the young people had the opportunity to openly think, question and discuss these topics. The nature of the semi-structured questions asked in these focus groups is outlined in Appendix 2. The level of being responsive towards the different views and opinions involved during the focus group sessions was essential to be able to recognise and judge what to pursue with the young people (Mason, 2002).

The choice of conducting focus group sessions was based on my judgement and experience that focus group sessions would provide the opportunity to engage young people in a more conversational format compared with the interrogation style that can be generated during individual interviews. This form of interaction is expected to generate a richer context influenced by the relationship between participants and the researcher, including aspects of conformity or censoring (Carey & Smith, 1994; Kitzinger, 1994). It was important to be aware of the influence being audio-recorded may have on stifling the conversational dialogue valued in this study (Mason, 2002).

It was hoped that the focus group sessions would allow the opportunity for the young people to bounce thoughts and opinions between themselves rather than relying on the researcher for direction. Participants could then question each other and re-evaluate and re-consider their own understandings. In this manner, young people could have more opportunity to be involved in their own decision-making process (Race, Hotch & Parker, 1994). This would increase the feeling of young people being valued as experts and working collaboratively with researchers (Goss & Leinbach, 1996).

The perceived limitations in using focus groups in contrast with other research methods include circumstances when participants are particularly shy or inarticulate within groups (Gibbs, 1997). In this study, the sensitive topic of mental illness could have been perceived as quite intimidating, discouraging those who were not very articulate or confident, or have communication problems. Focus group settings are not fully confidential or anonymous, which could discourage many young people from trusting others with sensitive or personal information (Gibbs, 1997). The approach needed from the AR should include qualities of listening empathically, the ability to ask gently probing questions and to practice regular reflection and clarification to benefit the interpersonal and intervention skills to engage the young participants (Bulpitt & Martin, 2010). Active listening was fundamental to respect the young person’s voice and ensure that verbal and non-verbal cues are picked up upon appropriately.

However, at the start of the focus groups that there was no intention for the young people to discuss any personal information in relation to mental health. Hence, a focus group setting was still arguably the right method for my research. It was important for the principal researcher to remain reflexive and distinguish my role as a researcher from a mental health nurse. This was imperative to prevent dialogue from becoming therapeutic in nature during the focus group sessions (Bulpitt & Martin, 2010).

During the focus group discussion, as the participants talked to each other, the topic of the research could naturally be led astray (Morgan, 1988). In this study, this perceived limitation was viewed as an advantage, as it would be a sign that the research was being directed to a certain extent by the young people rather than the AR. The open-ended approach of the focus groups could potentially allow young people to explore topics that the AR may not have approached or considered, hence shining new light on the topic.

Another perceived limitation was that, within focus groups, it is very difficult to identify individual views within the responses participants provide (Gibbs, 1997). The product of these views is contained within a specific context, and within a specific culture. The ability to show group norms within this interaction is helpful to provide insight into the social processes involved in the construction of young people's knowledge and understanding (Kitzinger, 1994). If the aim of the focus group sessions is to explore this specific culture shared among the young people, then focus groups are ideally set in exploring how young people respond within these contexts.

A mosaic participatory approach challenged the belief that age can prevent active participation in research (Clark, 2004; Clark and Moss, 2005). This involved engaging the young people in a range of different activities to triangulate diverse ways young people can express themselves through talking, drawing, and writing (Morrow, 2001a). One example these activities was a body mapping exercise (see Photo 3). This exercise involved the young people drawing around the outline of one of their peers who had to lie on the floor, and then each young person wrote a different word or drew an image associated with the experience of psychosis. This was an exercise recommended by Ennew & Plateau (2004) to supply a visual stimulus for young people to express their experiences of physical and emotional punishment. This method also evaluated the impact of a psychosocial programme to look at what caused pain or sickness, and how people could stay healthy (Armstrong et al., 2004). The advantage of using body mapping was to provide a fun, enjoyable, physical and interactive activity for young people (Crivello, Camfield & Woodhead, 2009).

The use of visual media was justified, such as video clips of people suffering from psychosis, to create a multidimensional quality for the discussion of psychosis, as it relates directly to the thickly-textured phenomenological experience (Mason, 2002) (see Appendix 2 for a list of websites). The use of such visual media can make the topic alive and real, creating more interest and enthusiasm and a stimulus for participants to discuss and interpret (Mason, 2002). These reactions include more chance of stimulating an emotional response and an effective method to encourage reflection (Morrow, 2001). These visual examples enabled young people to explore and stimulate discussion of similar situations or experiences which they or friends have had to deal with (Punch, 2002b). At the same time, the experience of using these clips in practice did meet similar challenges to those described by Punch (2002b). Time taken to play these video clips absorbed valuable time away from the focus group sessions and I also experienced a technical problem with the audio during one of the focus group sessions.

An adapted (minimised) diamond ranking post-it note activity enabled young people to identify and rank in order of importance where they obtained their knowledge about psychosis from (see Photo 1). This enabled the researcher to develop discussion with the young people about what the reason was for placing more significance on one factor than another (Clark, 2012). No presumed responses were provided to the young people, which normally occurred in the diamond response of 9 activity. This was because it was important to allow the young people themselves to write what they thought were the most important sources of knowledge without any presumptions. The importance of this type of activity has been the ability to obtain young people's opinions whilst not making assumptions about what they think (Clark, 2012).

This method was important, as it was initially difficult for young people to feel comfortable in talking with a stranger in a focus group environment. Writing down their thoughts, however, was a way in which they could express themselves in a more informal method, and made the young people move around the classroom to stick the post-it notes on the wall.

The use of a vignette about Luke (see Appendix 3) was utilised with the aim of leaving space for participants to define the situation in their own terms, how they would respond to a situation by stating what they would do, or how they would imagine the character of 'Luke' would react (Barter & Renold, 1999). This created freedom for the young people to have more control over the interaction within the focus group session and the ability to define the situation described in the vignette in their own terms (Barter & Renold, 1999). This was a useful icebreaker to develop rapport and introduce an experience that is not known by the research participants (Hazel, 1995). It creates a comfortable distance away from discussing private experiences, but responds to other people's experiences in a non-threatening environment (Barter & Renold, 1999). It is important to note that the inclusion of a ranking scale was not utilised in a quantitative manner. Instead, the scales were referred to in discussion to compare degrees of feeling comfortable/uncomfortable in their association with the character Luke.

Cue cards supplied a 'structure which, while scaffolding elicitation processes and responses, do not constrain or bias' (Lewis, Newton & Vials, 2008, p.27). The intention was for the cue cards to free the researcher from verbal leads and give participants time to handle the cards and get away from 'the rigid and limiting question-answer-response format of much adult-child talk' (Lewis, Newton & Vials, 2008, p.27). The cue cards had written questions from the semi-structured questions detailed Appendix 2. The use of these cards ensured that all the young people had a chance to answer the question when passed from one participant to the next until all participants had the chance to answer the question. However, this technique was not entirely successful as some young people just wanted to pass on the card as quickly as possible. The use of cue cards also restricted the nature of the interaction between the young people, reducing the advantage of using focus group sessions.

My choice of these techniques illustrated my belief and faith that young people were competent to be involved in my research if suitable activities were involved to increase engagement (Punch, 2002a; Clark, 2004; Clark and Moss, 2005). Arguments still exist that question, if children are competent social actors, why should there be special child-friendly methods needed in research (Punch, 2002a)? In fact, these methods are as much adult-friendly as they are child-friendly. This does not mean that using these interactive methods mean that young people are perceived as having different competencies to adults (Punch, 2002a).

There was unavoidably still direct regulation from the AR on how these participatory activities were used *on* young people without any consultation from the young people. Claims that the participatory methods used in these focus groups empowered the young people are questionable. For example, in Burke's

(2005) study the researcher claimed that giving the young people cameras empowered them. In fact, the cameras were still regulated by adults in terms of how they could be used (Gallacher and Gallagher, 2008). This influence has been criticised as creating the possibility of a ‘self-regulating’ young person within research, as the adult remained in charge of these activities (Clark & Moss, 2005; Prout, 2002).

On reflection, even though my intention in developing these participatory activities in the focus group sessions was to increase young people’s participation, the materials and structure of the focus groups were developed in a teaching session format. This was because as a teacher I instinctively created a structure that aimed to address all the objectives of the research presented in a PowerPoint presentation (see Appendix 5). This reduced some level of flexibility that I hoped the focus groups would generate, as the AR directed relevant questions and gave instructions to the young people about how to carry out the activity.

Moreover, the extent to which young people were empowered was dependent on their ability to express themselves autonomously, which risked excluding those less able to engage in the research activities (Ruddick, 2007). For example, those young people more confident to express their views were able to engage in direct debate, while those young people less confident were noticeably less willing to participate and more likely to conform to other young people’s views.

It became a natural progression to work with these young people further, not as research participants but as participants in the research process. Phase 2 allowed this progression to occur through research training sessions to develop these young people to become PRs.

4.5 Phase 2

Phase 2 of the research process utilised participatory peer research methodology to avoid the likely skew of accounts caused by the power differential experienced in Phase 1 between the AR and young people participants (Schäfer & Yarwood, 2008).

4.5.1 Data collection: Participatory peer research methodology

The definition of peer research is determined on the interpretation of the word ‘peer’. Murray (2006) identified two models as a means of conducting peer research; these are the community model and the professional model. The community model is where the PR is local to the community or the target group, creating more shared identity than just age within the college environment (Murray, 2006). In contrast, a professional model involves PRs who are trained for a specific time and purpose (Murray, 2006). The PRs only hold shared identity because of their age.

The PRs become, in effect, key informants by their recognised status as community members and their local knowledge (Manderson & Aaby, 1992). In this research peers are the same young people recruited in Phase 1 of the AR-led focus groups, defined by their age (16-17) and affiliation with the same educational institution. They held shared experience of receiving health education within their school education and knowledge of the background and interests of their peers recruited within their friendship groups. Hence a community model of peer research methodology was chosen based on the level of insider knowledge they could bring to this study, a more valuable asset than a professional PR to appreciate experiences and knowledge that may have gone unnoticed by researchers without the same level of familiarity with the research participants (Nind, 2014; Devotta et al., 2016).

Peer research methodology advocates the advantages of PRs involved in all stages of the research process. However, the extent of participation of young people within the research process does differ substantially (Hart, 1992). It is at times inappropriate or not possible for young people to engage in all stages of the research process. Nevertheless, the process would not have started without engagement within the peer research training sessions.

4.5.2 Peer research training

Peer research training involved the AR training the young people who had volunteered to become PRs. The training conducted lasted a total of six sessions of an hour each in the two colleges (content detailed in Appendix 4 and 5). In this section, a commentary about the importance of this training, and a critical discussion surrounding the influence using this training could have on the aims of using peer research methodology, will be provided.

Peer research training is essential to overcome one of the principal barriers in preventing children or young people from conducting their own research, the adult-orientated concern that young people have insufficient knowledge, understanding and research skills to be researchers (Kellett, 2010). Ethically, concern surrounds young people's lack of ability to deal with issues surrounding self-disclosure, confidentiality, and child protection issues. This concern is not age related, but universally applied to all researchers who are not trained. Most adults would not be able to conduct research appropriately without having the necessary research training (Kellett, 2010).

It was therefore important that these peer research training sessions focused on the importance of addressing the ethical issues of supplying informed consent and giving enough time for participants to make an informed choice. The PRs developed their own information leaflets about the research and ensured consent forms for participants were signed, based on the AR's consent forms with ethical approval (see Appendix 6 and 9).

The empowering influence of peer research training has been critiqued in how it implies that young people's involvement is dependent upon these adult-devised techniques (Gallacher & Gallagher, 2008; France, 1999; 2000). The provision of peer research training places PRs within an adult-orientated research world, perceived as needing to undergo this training phase before young people can be trusted or viewed as competent. The result is that the PRs could become substitute adults, and no longer perceived as peers by their research participants (France, 1999; 2000). This has the potential to produce tokenistic value of young people's participation, with false feelings of how empowered or involved young people are in the research.

Moreover, there is also criticism that peer research training has been a method to shape young people to conform to adult norms within research. A specific concern has surrounded the need for the PRs to value the need to be unbiased and aspire to a form of scientific rigour in their practice (Devotta et al., 2016). Kvale & Brinkmann (2009) illustrate the disadvantages of focusing on such a criterion and not acknowledging the benefits that PRs can offer through personal interaction not obtainable via a professional AR. The set of skills that PRs have can enable them to use their own personal discretion and be much more responsive to the participant’s answers. There is greater personal connection/interaction made, a skill not quantified but one that needs to be valued on its own merits (Devotta et al., 2016).

During the peer research training, one aim was to prepare the PRs how to be in control of aspects of the research procedure. This included aspects such as the location of the focus groups sessions, the focus of questions asked, the seating arrangement of the young people and control over the audio recording. This form of control could be argued to replicate the same power an AR would own, hence simply replacing the power differentials between peer participants and the PRs. PRs could end up in a powerful position vis-à-vis other young people through the influence of friendship dynamics (Kirby, 1999).

Highet (2003), for example, illustrated how different relationships and social interactions between young people within paired friendship interviews can influence how views, beliefs, and experiences are expressed. This included an increased ability to challenge adult discourses and, more specifically, the dynamic of close friendship bonds between male friends provided more insight into their private emotional worlds (Highet, 2003). The relationship developed during peer research training and focus group sessions provide a unique opportunity to consider how young people manage these social relationships with one another.

The decision was made for the PRs to work together in paired friendship groups to prepare their research material used in the focus group sessions, to recruit their participants and then to conduct the focus groups. Mayall (2000) praised the use of self-selected friendship pairs to create a supportive social context when children aged 5 and 6 chose a friend to take part in an interview. Mauthner (1997) similarly used paired interviews with children aged 5-9 to discuss healthy eating. This strategy supported the advantages of creating a comfortable relationship where participants were able to disagree with each other. It was hoped that these advantages would be reflected in the support that the young people would feel throughout their experience of engaging in peer research so that they would not feel unprepared or unsupported.

The peer research training sessions valued the PRs as experts with an understanding of their own youth subcultures (Mayall 2000; Alderson and Morrow 2004). Hence a central theme during the training involved co-operation between the young people and the AR. It was not perceived as an opportunity to mould the young people into substitute adults (France, 1999; 2000). The training assumed that the young people were competent agents and gave them the flexibility to develop their own research tools. The young people worked together in pairs, with the use of computers to generate their work, while I acted in a more supportive role. The training also actively involved discussion and scenario work that valued young people's thoughts and views about key issues that may arise during the research.

The training created the opportunity to develop research resources that were suitable, relevant, and engaging for young people. The young people developed their own leaflets explaining the nature of the research to recruit participants. The format and wording of these leaflets guided the student according to what they perceived were the advantages, disadvantages, ethical issues, and reasons for carrying out the research (see two examples in Appendix 9). The young people also developed and choose their own resources, including the use of imagery in the form of young people's drawings (see Drawings 1-5) and the use of photos of different individuals (see Images 2-5). There was also a 'blockbusters' quiz and a true or false activity developed as an icebreaker, while some young people developed their own fact sheets. Examples are provided in Appendix 9, although not all resource information used during the PR-led focus group sessions were provided to the AR.

The level of freedom and creativity built into the peer research training sessions prevented the focus group sessions led by PRs from becoming a replica of the AR-led focus group sessions held previously. The peer research training sessions allowed the young people to discuss and interpret the focus they wanted to take. It did not lead to a copying effect but stimulated a unique insight into what the young people felt was most important to explore among their peers.

Despite the advantages observed during the peer research training sessions, there were challenges including an apparent lack of priority taken by some PRs towards engaging in these sessions. Poor attendance and variability of preparation done by the different paired groups of young PRs was an indicator of this concern. Nevertheless, these individual PRs gave assurances that they were prepared and had been conducting preparations for their research focus groups independently. At the time of the study, I had doubts about whether these young people were sufficiently prepared to conduct the focus group sessions, which I found anxiety provoking.

On reflection, this perceived lack of engagement highlighted that the peer research sessions were flexible enough to provide young people with the freedom and trust to conduct the focus group sessions effectively. As argued by Gallacher & Gallagher (2008), it is important to recognise that during the research project the young people might act in unexpected uncontrolled ways. However, there were advantages embedded within this challenge as illustrated in the end result, as all the PRs did engage well in discussion exercises about their responsibilities as researchers and had worked independently to create resources necessary for their focus group sessions.

It was vital that Phase 2 of this study supplied time for young people to prepare themselves and feel comfortable enough to conduct their own focus groups. It was an opportunity to learn how the young people interpreted the research to shape it according to their own perspective. A great amount of trust was needed to value the peer researcher’s level of competency and ability to engage within the research process. The only way of assessing whether the preparation time was successful would be the outcome of Phase 3.

4.6 Phase 3

The next phase of the research started with the PRs recruiting their peer participants, followed by the implementation of their focus group sessions. The success and difficulties experienced in the recruitment stage of the peer research will be considered first.

4.6.1 Sampling framework: Recruitment of peer participants

The use of community PRs was an asset in terms of widening the recruitment of participants involved in this research. The PRs had insider knowledge and access to participants that the AR did not have. There was no reliance on having to approach teachers to recruit potential participants and there was more flexibility when the focus groups were held. Thus, twenty-four participants were recruited into the study to participate in peer-led focus groups.

The PRs worked in pairs to conduct their recruitment from friendship groups within the college. The inclusion criteria were that participants were aged 16-17, were available to take part in the focus groups during the time and location decided by the PRs and had agreed/understood what the research would involve. A minimum of 3 and maximum of 5 participants in each focus group was decided to be an appropriate and achievable number to recruit by the PRs in order for the focus group to generate a good level of discussion. This inclusion criterion was valuable as it included young people studying non-health or non-social science-related subjects, and this improved the gender imbalance. This meant a wider range of views and opinions could be generated from participants not necessarily knowledgeable or interested in the research topic.

The influence that the PRs could hold on young people to take part is also an advantage in terms of not having to go through a gatekeeper or rely solely on the willingness of participants to volunteer to an AR. This widened participation of young people who would not normally volunteer, as the participants may feel more comfortable to agree, or feel more obliged to take part to help their friends. The resulting possibility is more freedom of expression of ideas during informal interaction created by this type of recruitment (Wilkinson, 1998; Schäfer & Yarwood, 2008).

However, at the same time, this perceived advantage posed an ethical risk that peer participants might feel obliged to participate. This is because, within friendship groups, peer pressure would have been an influence used during recruitment. Peer participants are not likely to want to let their friends down and may take part even though they are not interested or even want to be involved. It was therefore important that the same ethical considerations were addressed during the recruitment process as discussed during the ARFGS. This was an area where flexibility could not be afforded in the training of the young people, ensuring that all PRs had obtained informed consent.

Kellett (2010) also voiced concern surrounding the possibility that if the PRs recruited were white, articulate middle-class young people, they would possess fewer common characteristics with their peer participants. Peer participants recruited would then be more passive in nature compared with the energetic, outgoing, and confident PRs (Kirby, Laws & Pettitt, 2004). There exists the potential that the peer participants will lose their voice considering the characteristics of the PRs (Alderson, 2008).

Notwithstanding the potential advantages of this recruitment strategy, it also involved some practical challenges. In one college, the recruitment of participants was a much more difficult and uncertain challenge. I first became aware of this difficulty when the PRs contacted me by email to inform me that they had difficulty in recruiting participants due to lack of interest and difficulty in getting the young people together to conduct the focus groups. In response, I was able to supply £5 High Street gift vouchers as an incentive to offer their participants. This solution resolved this recruitment problem, illustrating how important incentives could be in the recruitment process even within friendship groups.

Ethically, one could question whether it was fair that one college offered vouchers to its peer participants when the other college had not. However, it was important to recognise the need to be flexible in the different contexts and environments these colleges held when conducting this research. The PR’s request was also considered reasonable.

The second challenge faced in the same college was when the college tutor expressed concerns that the PRs were interrupting lessons to recruit their participants, causing young people to be late for lessons. The tutor expressed her displeasure that the PRs were asking other college teachers to ask for volunteers for them. In response to these concerns, the tutor asked me to take responsibility for the PRs and their recruitment, as it was my research. The teacher's expectations of the primary researcher and the young people's role as PRs were in conflict. The young people were in a position of authority which conflicted with expectations of a student's role.

The young person's position in recruiting potential participants was challenging if they did not have support from adults. This exposed a weakness in this methodological approach, as recruitment was not entirely independent from the support of their teachers and the AR. This experience shows the difficulty young people experience when faced with expectations and rules enforced by adults. However, when the young people faced these challenges it was their perseverance that overcame these barriers, showing negotiation skills to find funding for vouchers, and learning not to rely on the support of their college teachers to help with their recruitment.

4.6.2 Data collection: PRFGS

The anxiety that I experienced during this phase of the research was exacerbated by the lack of control I held. There was a high degree of unpredictability and uncertainty that remained throughout this phase of the research, particularly surrounding whether the young people would even conduct the focus groups and their ability to conduct the research to an academic and ethical standard that would support the study.

Linked to the lack of support reported in D college from their tutor in the recruitment process, there were also similar difficulties in gaining support to help the PRs organise their focus groups. From the tutor's perspective, the young people's requests to organise a time to conduct the focus group involved them interrupting classes. The teacher was also not pleased that young people were utilising classrooms to conduct their focus group sessions without an adult present, since this college has a policy of not allowing open access to classrooms which were locked if not in use, increasing reliance on the support of their college tutors to gain access to a classroom.

Nevertheless, the young people were able to challenge the rules about adult presence being necessary to have access to classrooms. They also showed their ability to find a time suitable for all their participants to engage in the focus groups and contacted their IT department to give them access to audio recording devices. These qualities give credit to the skills of young people without any need for adult intervention or support.

The problems experienced in D college were different in comparison with S college involved in the study. In S college there were no such access restrictions in place for the PRs to gain access to classroom environments to conduct their focus group sessions. There was also a different attitude expressed by the college tutor, who was more willing to offer support to the young people in facilitating the focus group sessions. The support the young people received from their college environment was certainly influential to determine the effectiveness of the focus group sessions.

Unfortunately, S college did experience another type of unforeseen problem. This problem surrounded the young people's reliance on their college's IT support to download their audio recording. The technical problem that occurred resulted in one focus group's recording being deleted. This event was traumatic for the PRs and myself, and I thought that the PRs would choose not to conduct another focus group session. In fact, the PRs decided that they would conduct another focus group and reflected on their earlier attempt and thought of different ways in which to conduct the session and obtain a different selection of participants. This event illustrated the resolve and commitment shown by the PRs.

The next problem met from the principal researcher's perspective was the fact that some of the PRs discarded the material they utilised during their focus group sessions. This occurred despite requests made to the PRs to keep all the material they utilised. On reflection, to prevent these materials being discarded I should have intervened after each of the focus groups had been conducted. Nevertheless, this occurrence illustrates how the PRFGS (PR Focus Group Sessions) depended and were based on the trust established between the researcher and the PRs.

On reviewing the PRs’ recordings, I was also initially concerned that the majority of recordings lasted under an hour, and each varied in length of time. Two of the focus group sessions lasted 24 and 23 minutes, while the other focus groups lasted from 30 minutes to 48 minutes. The exception to this was a focus group that lasted 80 minutes. My first thought was that this could be a sign that the focus groups were not conducted as thoroughly as needed to gain the views, thoughts, and attitudes of the participants in attendance. This was illustrated when the focus group session which lasted the longest, 80 minutes, was the focus group that was repeated after the young people’s earlier recording had been deleted. Feedback from these PRs was that they had learnt and reflected on their earlier experiences, which informed them how to conduct their next focus group more effectively from their perspective. I would agree that this focus group was much more structured by the resources and questions posed by the young people, but this did not necessarily mean that the quality of responses was any greater.

In fact, my concerns and anxieties only illustrated my own thoughts about the possible weaknesses of utilising PRs and their perceived lack of research skills. The PRs instead showed that in a brief period they proved the advantages of being able to interact in less directed conversation and become more background figures (Bloor et al 2001). Hence, the PRs spent less time prompting or explaining instructions and spent more time just listening to their peers. This was a quality lacking in comparison with the AR, whom participants looked up to for more guidance.

The use of resources that the PRs independently developed was one factor that enabled the focus group discussions to take the form that it developed into. This involved mirroring some of the activities utilised during the ARFGS, such as the use of post-it notes and body mapping. Unfortunately, as mentioned previously, the PRs discarded the body maps, and most of the post-its detailing where the peer participants had obtained knowledge about psychosis (see Photo 2).

Nevertheless, the information discussed on the body map and post-it notes were recorded verbally and have not been excluded by the fact that the resources have been lost. There were also different approaches, which involved asking peer participants to draw someone with psychosis, and the use of photos of different individuals (politicians, celebrities, young people, Goth images and different emotions) (see Images 2-5). These activities generated discussion in a direction perceived to be relevant to the young people when understanding the experience of psychosis.

The use of PRs was beneficial in that participants appeared to reveal information not normally disclosed to an AR (Murray, 2006; Saunders & Broad, 1997). The reason for this advantage has been explained in terms of the ability for PRs to develop more rapport and trust with their participants, giving participants the chance to talk more openly and honestly within a familiar cultural framework (Warren, 2000; Kilpatrick et al., 2007). A more relaxed and less formal environment was developed within these focus groups without participants feeling looked down on by an AR (Smith et al., 2002; Bland & Atweh, 2007). No judgment was made on young people’s possible lack of competence or knowledge about mental health, resulting in less need for young people to sugar coat their answers to provide socially acceptable or perceived right answers (Burns & Schubotz, 2009). This created the chance to challenge the possible multiple interpretations involved in how young people create meaning outside an adult-dominated world (Grundy, 1996).

The possibility that PRs would be falsely viewed by their fellow peer participants as experts in the research topic was not evidenced during the focus group sessions. Discussions were not reliant on the direction of the PR but involved more freedom and interaction between the peer participants. There was no sign that the PRs dominated discussions due to interpreting participation in this research as school work (Fraser et al., 2004). It was the peer participants who were more opinionated in their views and led the dialogue within the focus group sessions.

There were, however, potential disadvantages noticed when conducting the PRFGS. One of these perceived disadvantages was the extent of conformity in the discussions held within the PRFGS compared with the AR-led focus groups. The level of conformity incurred lack of debate or questioning about the issues discussed. The possible explanations for this will now follow.

One explanation for this could be due to how the dialogue between friends may increase potential for respondent conformity and self-censoring of views at odds with the majority view (Carey & Smith, 1994; Kitzinger, 1994). Participants may feel uncomfortable and incompetent about their lack of knowledge and understanding among their peers (Allen, 2009) resulting in participants 'slanting their responses to avoid loss of face with a compatriot' (Padgett, 2008, p116). However, this potential disadvantage illustrates how social interaction between peers can influence discussions when an adult is not present.

Another explanation could be the lack of research skills the PRs owned. For example, there were times during the focus groups where there were probing opportunities missed by the PRs that could have increased follow up leads or sought clarification (Bloor et al., 2001). In fact, the very fact that the PRs were not experts allowed participants to not feel that they needed to enter an academic discussion. What followed was a more open conversation, and an alternative insight that ARs were not aware of, or would not have previously considered, was featured (Smith et al., 2002).

One area of insight provided by using PRs has been the ability to create a greater understanding of young people's peer culture. Peer culture has been defined as 'a stable set of activities or routines, artefacts, values and concerns that children produce and share in interaction with peers' (Corsaro & Eden, 1990, p197). Morrow (2001a) illustrated how young people develop their own concepts, language, and culture through interaction with other children that can be difficult for adults to access or interpret. Whereas young people as researchers can share similar social lived experience (for example the influence of media, popular youth culture and educational experiences) and common language with their participants, increasing awareness of local and shared meanings and experiences young people engage in when discussing topics such as mental health (Kyratzis, 2004; Kirby, 1999; Smith, Monaghan & Broad, 2002).

It is this level of expertise that challenges the traditional skills-based criteria measurement of competency (Alderson, 2008; Faulkner & Woodhead, 2008). This emic knowledge has potential in shedding new light on understanding the topic from the young person’s perspective (Cleaver, 2001; Moore, Saunders & McArther, 2011; Smith et al, 2002). It also prevents ARs from assuming or placing official perspectives on health that do not accurately reflect young people’s framework of health needs (Spencer, 2013).

This section overviewed the three phases of my research methods. It has explored the various advantages, barriers, difficulties and ethical issues experienced through the process of recruitment, and the actual development of the research sessions to the focus group sessions themselves.

My next section of this methodology chapter will describe how and why I utilised a thematic analysis framework when considering the results of the focus group sessions. This will include an acknowledgement that this stage has not conformed to the ideal participatory approach initially planned for this study.

4.7 Data analysis

The data analysis stage holds the keys to the interpretation and presentation of research data. This section shall illustrate the reason for the choice taken in conducting thematic analysis, followed by a description of how thematic analysis was conducted.

4.7.1 Choice of analytical method

Ideally, in the tradition of peer research methodology, the young people involved in this research should have been involved in the data analysis stage. This is because authors such as Clark (2004), McLaughlin (2005), Coad & Evans (2008) and Kellett (2011) have criticised peer research methods as being tokenistic in terms of assigning young people to collect data but have been excluded from analysing and disseminating the data. This is because some researchers have argued that these stages are too intellectually and emotionally challenging for young people (Holland et al., 2010).

In fact, this was the original intention of the research, but unfortunately the young people expressed they did not want to be involved. The reason for young people not wanting to get involved in this stage was due to existing social/educational pressures, practical constraints, and lack of interest. It felt inappropriate to pressurise the young people, placing them in a position that demanded extra time and responsibility in the analysis process, which they were not interested or willing to be involved in.

I needed to be realistic about expectations placed on young people about their level of participation within research. Young people did not want to continue to be involved in all stages of the research process, including the analysis and dissemination of their own results. For the young people to have been involved in this stage of analysis would have demanded more of the young people's time to gain assess and training to utilise the NVivo software and resources to disseminate their results. In these circumstances to try and push this level of participation in the research would not be empowering.

The consequence of not having the PRs involved in the analysis stage meant it was my responsibility to conduct the analysis. Following the aims of the research, an inductive approach, coding the data using a thematic analysis framework (Burnard et al., 2008; Burnard, 1994; Burnard, 1991), was decided to be the best form of analysis. This judgement was based on the advantages this form of analysis gave me when dealing with such a large body of data from multiple focus groups, creating the ability to develop a useful summary and rich description of the key features identified in the study.

The thematic analysis conducted in this study helped me highlight areas of similarity and difference across the adult-led and peer researcher focus groups. In return, the analysis created a discussion of unanticipated insights within the data. This form of analysis reduced any prior assumptions made when interpreting the data collected, but instead allowed me to relate to the existing literature as a framework – specifically in this analysis the use of Haslam's (2005; 2007) folk psychiatry model. There was no intention to set this model as a framework to my analysis, but it was apparent during the thematic analysis that it was a useful to refer to in order to explain the data. A detailed discussion will now follow how the analysis was conducted.

4.7.2 Thematic analysis

The first stage of my analysis was to become immersed within the data, becoming familiar with the depth and breadth of the content of the data collected. To do this, I first transcribed the focus group sessions that I had conducted, then repeatedly read all the data collected, listening to the audio recordings together with the professionally transcribed scripts to check for accuracy. This process was extremely time-consuming and frustrating, especially when the audio was difficult to hear at times.

On reflection this stage provided me with good grounding to become familiar with the data and act as an interpretative phase to create meaning (Oliver, Serovich & Mason, 2005). During this process, I was continuously involved in note taking to search for meanings and patterns that could be named. This process allowed the analysis to provide a rationale for the themes that were developed.

The transcripts of the audio were loaded into NVivo 8.0 software for data management. This software enabled me to count and group the number of data items and data extracts relevant to the production of initial codes from the data. This involved deriving an initial coding framework from the data; the codes identified features from the data that appeared interesting and could be organised into meaningful groups. Any data that supports or expands knowledge around a code was then attributed to that code.

During the coding process, I tried to avoid a reductionist approach as I did not want my analysis to exclude potentially significant elements of the data. When coding, it was important to keep some of the contexts that surrounded the individual codes used, and this strategy helped aid the rationale that lay behind the coding framework. For example, there were larger codes such as ‘image’ that were broken down into smaller codes related to the imagery young people associated with psychosis, such as ‘personal hygiene’, ‘age’, ‘gender’, ‘social class’ and even ‘gothic’. This was especially important when many of the codes established actually fitted into many different themes. The result was that, at times, there were tensions and inconsistencies created across the data items and maintaining the context of these codes helped explain my discussion why these tensions had arisen.

When the analysis turned towards sorting the different codes into potential themes, there was much discussion about the potential relationships that existed between the codes, themes, and sub-themes within them, but also codes that did not seem to fit into the themes that were generated. Overall, this process helped to form an impression of the significance of individual themes but did not yet conclude whether the themes needed to be either further refined, combined, or even discarded altogether. Hence, the initial themes that were formed needed further review. During this stage, there were times where the data was either too diverse to form a theme or there was not enough data to support the creation of a theme. In these cases, the data held within the themes needed review to ensure that there was a clear distinction proven between the themes. This also involved, at times, the need for re-coding, where the flexibility of thematic analysis proved invaluable in producing an overall story in the themes that were produced.

The themes eventually produced were vital in creating a coherent narrative to the story told about the data collected. It was important that the themes and codes within them were organised in a manner that explained why this theme was interesting and fit into the broader overall story in relation to the research questions, and did not try to cover too much or become too diverse/overlapping when considering the relationship between the themes/sub-themes that were developed.

During these decision-making steps of my analysis, it was important that an inductive approach ensured that the themes created were linked to the data, rather than driven by existing theory (Braun & Clarke, 2006). The researcher’s aims or theoretical interests were not used to drive the process of analysis, but to organise the findings *without* trying to fit the analysis into a pre-existing coding frame or my own preconceptions. However, it was apparent during my analysis that it was useful to relate the themes developed to existing literature. This was important in order illustrate how the data has challenged and agreed with latest theorising that exist in this field of study.

Realistically researchers cannot free themselves entirely from their theoretical and epistemological thoughts when conducting research. I was aware of the danger and accusations placed on past research studies where ARs have in their analysis developed themes related to their own interests, rather than the interests of the young people (Ezzy, 2002). This was why an inductive approach was vital and why my initial plan was to involve the young people in the analysis stage.

To maximise and protect the credibility of my analysis it was vital to be continuously reflective in my analysis; consciously aware how my theoretical and epistemological standing could influence how the data was interpreted. I also provided a sample of the transcripts to be coded by a colleague (familiar with thematic analysis) to be compared with the my own coded transcripts. The result from this comparison illustrated similar assigning codes, but variations of specific labels. Coding stays very subjective, but overall agreement indicates some good level of transparency in the analysis (Armstrong et al., 1997).

4.8 Reflection

The challenges that existed when conducting this research were numerous, and at times the peer research methodology process felt very unpredictable and uncontrollable. Despite these challenges, the outcome of using PRs was an asset in terms of the nature of the data generated and the way the young people became more involved in the research process.

Peer research methodology has given the young people involved in the research the experience of developing their own research skills. Feedback from 11 of the 13 PRs (see Appendix 2) showed that organisational skills, the importance of considering ethical issues in research, using a recorder (technical skills) and how to approach and engage participants during their focus group sessions were some of the skills they had felt were increased during this experience. The PRs particularly enjoyed engaging in discussion and exploring different opinions and thoughts about psychosis with their different peers. They appreciated the research process involved and the importance attached to obtaining qualitative data.

Not all the PRs involved in this research were positive about the experience (see Appendix 2 for more details). These PRs expressed frustration that they missed the same class every Friday morning, which meant that they had to do further catch-up sessions. They also experienced problems of engaging participants during the focus group sessions, which included problems with organisation and the recruitment process. Interestingly one response from a PR stated they did not feel that there was a transfer of power as a researcher in this research project, as they were ‘still doing it for someone else’. This is a valid point and illustrates one of the main flaws of this research, as there is no denying that the AR was still in control of the direction and topic of this research.

Nevertheless, despite one PR feeling that they were being used by the AR, the other responses seemed to show more positive feelings related to becoming a ‘PR’. This was related to the feeling of increased control and independence, but this level of responsibility was met with a feeling of difficulty in engaging participants, being prepared enough, having the ability to ask tough questions and an overall lack of confidence in having the right skills as a researcher. All feelings however that are still relevant to professional researchers.

The benefits of peer research methodology were interpreted by the PRs as providing a comfortable environment to open dialogue about psychosis. This resulted in more willingness to disclose information and be more truthful in their answers and develop different views. On the other hand, there were also experiences of feeling awkward in these situations, feeling difficult to remain composed and becoming more nervous in front of friends. The different social dimension that peer research brings to research is more complex than simply avoiding the demand characteristics discussed in relation to the influence of an AR.

I have also personally learnt a lot from this experience. I have become more aware of how research methods need to consider and appreciate the involvement of young people in research. I have reflected on my own involvement within the focus group sessions held, and how this has had an influence on young people’s discourse. I have also learnt more about myself as a researcher in terms of the extent to which I was comfortable in not having control over the research project itself when having to rely on young people as researchers. This was the most daunting and apprehensive feature of the research.

One important lesson learnt was the importance of listening, being respectful and valuing young people’s involvement in research. This involved being flexible in terms of understanding young people’s needs, and trusting their ability to engage in the research process. Examples of these challenges occurred when young people met resistance while trying to recruit other young people and when addressing the gatekeeper’s concerns. Non-compliance shown during attendance of the peer research training sessions was also concerning. Each of these challenges was addressed successfully by working cooperatively with the young people and enabling a level of independence to grow, allowing freedom and creativity to develop through the research. To achieve this, a balancing act had to address the power imbalance faced by the young people within their college environment.

The main change that resulted from this process was the acknowledgement that the young people were unable to be involved in the analysis stage of my research. This opportunity would have been invaluable to prevent adult-orientated assumptions and misconceptions from infiltrating the process of analysis. However, at the same time, young PRs could not bear the responsibility of this process as well as addressing their own personal and academic needs. Moreover, the issue of ownership of this research was called into question if I utilised PRs to conduct analysis, as co-authorship with young people was not a workable choice for this PhD thesis.

Nevertheless, my methodological approach widened the social constructionist perspective of the understanding and interpretation of psychosis. Valuable discussion points related to young people’s literacy about psychosis should inform future literacy developments. This has been achieved through the process of inductive analysis that has been related back to existing literature in order to understand how the young people’s voice has fit or not within these theoretical frameworks. These discussion points will be explained in the next chapter combined with the results of my analysis.

Chapter 5: Analysis and Discussion

5.1 Introduction

In my literature review it was highlighted that the complexity of terminology involved in mental health, and the interpretation of such terminology, has not been fully appreciated when attempting to understand young people’s comprehension of mental health. This is one of the focal areas that this research attempts to redress, opening a social constructionist perspective of understanding psychosis not limited within a biomedical framework.

The next step will be to build upon existing literature that has focused on obtaining young people’s views on their mental health literacy needs. A focus will be taken on specifically addressing what approaches are understood to be most appropriate or effective for the young people, and what rationale has been put forward by the young people. This will draw upon the existing literature that has already tried to evaluate the efforts of mental health promotional approaches utilised within the school setting. The main difference in this research is that no set agenda or pedagogical approach has been advocated. The page was purposefully left blank to allow young people to have a stronger influence on what they think their literacy needs are.

5.2 Aim 1: To explore young people’s understandings of psychosis

As stated throughout my thesis it was strongly felt that the first aim should be to find out what existing knowledge and understanding young people hold about psychosis before finding out what literacy intervention is needed. Many of the earlier literacy interventions considered have not carried out this first task. My research aimed to address this problem by being more responsive to young people’s existing knowledge and understanding surrounding psychosis.

5.2.1 Introduction

Most research that has investigated young people’s knowledge of mental illness has readily interpreted young people’s perceived knowledge deficits as based on the criteria of modern psychiatry. Kraepelin (1920) assumption that biological and genetic factors are the primary elements of mental illness has been unquestioned and continues to dominate formal understandings of mental illness within contemporary Western society (Ripke et al., 2014; Wray et al., 2018).

In this chapter, my argument is that such a criterion unjustifiably judges young people's level of literacy inaccurately, neglecting a holistic consideration. Attribution theory limits the ability to understand lay conceptions of mental disorders to controllability and stability in terms of the causes of mental disorders, without considering an explanation of the motives that surround the behaviour (Weiner, 1995).

Haslam's (2005; 2007) folk psychiatry model has been related to during this analysis to understand how young people rationalise their understanding about experiences of psychosis. The aim of relating my thematic analysis to this model is to explore the complexity that surrounds young people's existing knowledge and understanding, increasing the value and level of appreciation of young people's existing literacy.

The rationale behind this aim is to enable future strategies for improving literacy to be aware of young people's existing knowledge and understanding. It is inappropriate to assume that young people are stigmatising or stereotyping without appreciating the context and meaning young people have attached to the experiences of psychosis. Instead, it is important to have the opportunity to explore and understand what is important for young people.

My first discussion point will examine the extent to which the research results mirrored an understanding of psychosis based on a biomedical explanation of the main causes of developing psychosis. This discussion fits within the medicalising dimension suggested by Haslam (2005; 2007), but also illustrates the ability for young people to explain the context for the reasons why this may or may not be a potential cause.

5.2.2 RQ1: To what extent does a medically-constructed discourse around psychosis influence young people's discussions about psychosis?

The findings of the ARFGS sessions showed a stronger element of conformity when explaining the biogenetic causes of psychosis. Within previous evaluated MHL interventions, a biogenetic explanation was used as a criterion to determine an individual's level of literacy (Read et al., 2006; Spitzer & Cameron, 1995). The benefits of utilising biogenetic explanations for the causes of psychosis were linked to improving young people's ability to improve diagnosis and help early professional help-seeking behaviour (Secker, Armstrong & Hill, 1999; Kelly, Jorm & Wright, 2007; Sakellari et al., 2011). The perceived benefits of young people conforming to a biogenetic explanation for psychosis seem to have influenced the young people's responses towards the AR.

There was also a significant amount of debate held on the possible different causes, illustrating open-mindedness and awareness of the ongoing academic debates that surround the causes of psychosis (Bentall, 2003; Szasz, 1960). During the PRFGS there were more statements with less conformity to a biogenetic-orientated explanation of the causes of psychosis. A more social interpretation and meaning considered the possible reasons for the causes of psychosis. Figure 6 provides a summary of the main themes discussed by the young people to explain the possible aetiology of psychosis. These themes will be discussed in turn:

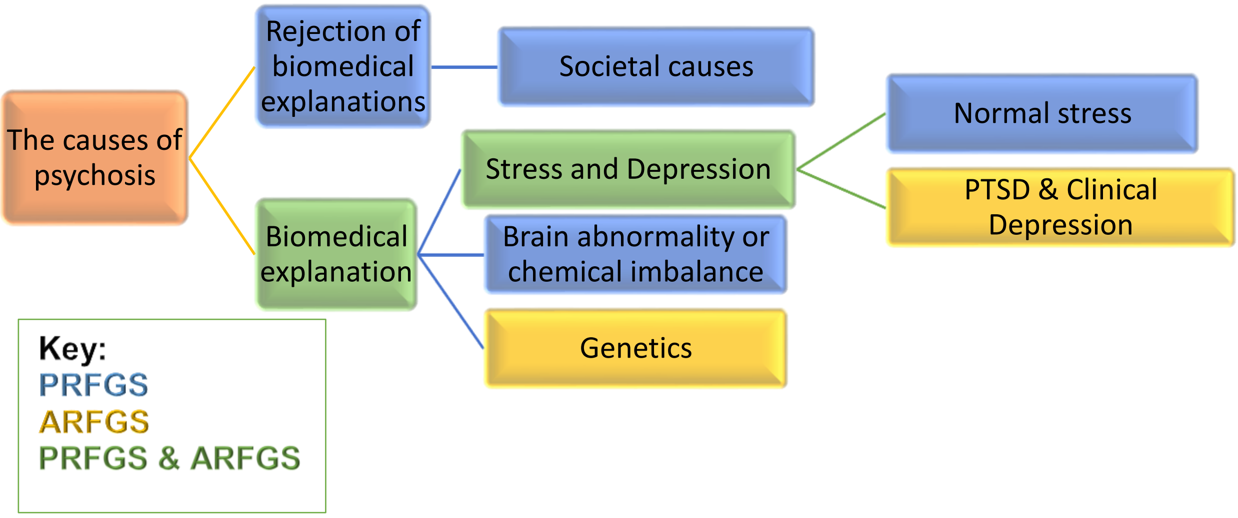


Figure 6: Understandings of aetiology as accounted for in the research

5.2.2.1 A social diagnosis?

One of the surprising features of the data collected during the PRFGS was the way some of the young people focused away from considering internal causes of psychosis, yet increased consideration of the influences that external social factors may have. This follows the arguments made by the anti-psychiatry ideas popularised by Szasz (1960), as he distinguished certain mental illnesses as 'problems of living', rather than symptoms of an illness.

Thus, the young people followed on from this argument by showing that judgements made against certain individuals, specifically the homeless, increased the likelihood of having a mental illness. A social moral judgement about the presentation of these individuals was made which did not follow any positivist criterion:

> R1: I would say just because homeless people see even talking to themselves doesn't mean they necessarily have schizophrenia or a mental disorder its just because they're quite withdrawn from society and because of the position they're in they may even blame society for it so.

These comments blamed social influences as being disabling and weakening for the individual's position as much as the illness itself. Szasz (1960) concurred that the opportunity to define someone as mentally ill creates the opportunity to socially control behaviour by psychiatric practice.

The problems of living associated with being homeless illustrates the need expressed by the young people not to necessarily label such behaviour inaccurately, but to understand the behaviour within the social context it is being experienced. Laing, in his work *The Divided Self* (1960) moved beyond the simple denial of mental illness towards making sense of the experience of schizophrenia. R1 commented on the impact that stigma had on the judgement given to those who were homeless:

> R1: They kind of portrayed them as being crazy and kind of not socially acceptable.

One could argue that the young person's concern about social influences on the prospect of developing psychosis could be based on the process of social causation, in which the influence of being socially disadvantaged increases the probability of developing a mental illness. However, it appears that the young people were dismissive of the fact that this was simply because of the influence of class, and expressed that the cause was more entrenched in how society perceived psychosis:

> R4: I don't think it would depend on your social class whether you like suffer from it or anything, I just think some people might not talk about it within certain social situations.

The perceived causes of psychosis were linked to the degree of stigma and stereotyping that exists among the values of today's society. In terms of evaluating the extent of young people's stigma and discrimination, such awareness of the impact of social understandings illustrates that young people were cautious about the influence that diagnosis could have an impact on the individual's position in society. This supports the mixed blessing model in terms of the need to be cautious in promoting a biogenetic explanation, as it could increase levels of social distancing (Haslam & Kvaale, 2015).

The fact that the young people were able to question whether experiences of psychosis necessarily had to be diagnosed takes away the first step of pathologising such abnormal behaviour in Haslam's (2005; 2007) folk psychiatry model. Young people's existing belief structures about psychosis require further consideration. Parallels of the misinterpretation of women's 'depression literacy' (Parslow & Jorm, 2002) have been illustrated by Gattuso, Fullagar & Young's (2005) attempt to provide more insight into the complex understanding of the social meaning attached to depression.

Instead, the power threat meaning (PTM) framework appreciates how young people have accommodated the possible cause of psychosis within a social and relational context that exists on a continuum with normal behaviour (Johnstone et al., 2018). It is important to consider the impact that being homeless can have on the belief of having psychosis. The PTM framework gives the opportunity to credit and create space for young people to follow an alternative dialogue about the causes of psychosis. The factor of homelessness acknowledges the operation of power in terms of material and economic disadvantage. This concludes the importance of not separating the biogenetic causes of psychosis from the social and interpersonal environment of the individual experiencing psychosis.

A focus will now turn towards how sense was made of the impact of stress and depression in terms of an aetiological explanation of psychosis.

5.2.2.2 The impact of stress and depression

Stress was explained by young people as a possible psychological factor increasing the risk of developing a psychotic episode. During the PRFGS, stress was described as an explanation of why it was thought that an adult, rather than a young person, would be more likely to develop a psychotic episode:

> Q: Just because of the stress I mean, it depends how you're going through it
> R4: Yeah like at eight you're supposed to be like carefree aren't you and you're supposed to have like no worries or anything
> R1: Associate generally with old people having it due to stress

This explanation correlates with Haslam's (2005; 2007) psychological dimension by showing that adverse lived experience was related to a greater risk of developing psychosis. There was no blame or moralising attached to this experience but it was viewed as an outcome of general stress you experienced when you got older. This response indirectly suggested that it was dependant on the extent the individual was resilient and could cope with different forms of stresses, which differed depending on your age.

This dialogue agrees with previous research that has illustrated the potential discrepancies that have occurred when considering an adult-orientated perception of what wellbeing means for the young person (Dex & Hollingworth, 2012; Naylor et al., 2009; Armstrong, Hill & Secker, 2000; Sixsmith et al., 2007). In this dialogue, young people perceive the term stress as an adult-orientated concept, which is not relevant for the young person's life. This confirms results from Naylor et al. (2009) and Armstrong, Hill & Secker (2000) that, from an adult perspective, the young person's own mental health wellbeing is trivialised and devalued in light of an adult's own problems.

There was also no perceived belief when the young people discussed the effect of life stresses that this would mean an abnormal amount of stress in one's life. The discourse orientated by the young people fits within the PTM framework of understanding how psychological causes are determined by the individual’s social and relational context, on a continuum with normal behaviour. We must, therefore, be cautious not to misinterpret the meaning young people attach to the term ‘stress’ in relation to serious mental health experiences such as psychosis. Dex & Hollingworth (2012), for example, show the dangers of misinterpretation from an adult perspective, which would normally frame such discussions of stress within a clinical framework.

In fact, during the ARFGS, there was a contrast in the meaning given to the term stress as a possible psychological cause of psychosis. This was directed towards a discussion about the possible links between post-traumatic stress disorder (PTSD) and psychosis. This involved describing someone re-experiencing past horrific events:

> C: something bad that has happened in the past that is catching up with him and he feels like whatever exists suddenly he is back in the past and is catching up with him now and he still thinks it is bad
> C: it can be a severe situation don’t know you might have an accident I don’t know being in a really bad accident where you seen horrific things

The motivations for C linking psychosis with PTSD seem to confirm previous research that has warned against discrepancies attached to the meaning of wellbeing for young people (Dex & Hollingworth, 2012; Naylor et al., 2009; Armstrong, Hill & Secker, 2000; Sixsmith et al., 2007). This is because C’s response when asked to supply a diagnostic cause aimed at conforming within a professional psychological dialogue. The effect of this dialogue increased the severity of the psychological causes and placed the experience of psychosis outside the normal day-to-day stresses of life.

It appears that caution is required when considering the terminology involved in the discourse of mental health, as this can be influential in determining whether young people can relate these experiences to their own mental health wellbeing (Armstrong, Hill & Secker, 2000). The reason for not seeming to be able to engage in a discussion about mental health wellbeing may lie in the expectations placed on the young people to respond in a diagnostic framework. These results suggest that taking away adult influence can avoid adult concepts influencing the generation of meaning young people construct with regards to mental wellbeing

(Sixsmith et al., 2007). This increased the ability for young people to place psychosis within a wellbeing framework during the PRFGS, compared with the ARFGS where there was more likelihood of utilising a diagnostic framework, as illustrated when using the term ‘depression’:

> H: I think it’s from depression you are not mentally stable so your mind is sort of messed
> C: because at the end of the day psychosis depression is a form of psychosis

This illustrates a tendency not to differentiate between different diagnostic categories, or simply a level of confusion over the technical meaning attached to depression. Different public attitudes towards different mental illnesses, however has influenced the meaning given to psychosis through a discussion about depression (Crisp et al., 2000). More negative imagery has been associated with the diagnosis of schizophrenia than depression or PTSD (Amanas, 2008; Angermayer et al., 2004). Hence, the effect during the ARFGS to discuss the aetiology within this diagnostic terminology has reduced the level of stigma attached to the experience of psychosis.

Relating psychosis to PTSD and depression enabled the young people to show the value of professional psychological and medical support and emphasise that hope was not all lost. These views relate to Haslam’s (2005; 2007) medicalising and psychological dimension and enabled young people to justify the reason for these individuals acting in this way without any moral responsibility. However, it also reduces the ability of young people to relate to the experience in terms of their own mental wellbeing.

In contrast, during the PRFGS, there was more uncertainty when young people were made to feel that they must conform to a diagnostic criterion set out by the PRs. This was evident in a true or false exercise developed by the PRs:

> Q: Right, symptoms of psychosis can occur three to seven days after pregnancy triggered by severe stress or anxiety, severe depression or sleep deprivation. Do you think this is true or false?
> R4: True because you get postnatal depression.
> Q: So you think psychosis is linked to depression and pregnancy then?
> R4: No. I don’t know about postnatal depression but.
> Q1: So you think that links with psychosis?
> R4: I don’t know, I’m confused.

> R2: Yeah because sometimes it's like 'R4' said, post-natal depression like in some severe cases people actually kill their children

This example mirrors a true or false exercise Stuart (2006) utilised in assessing young people's literacy and may demonstrate how the PRs have been shaped and directed to act within a research agenda shaped by the AR (Gallagher & Gallagher, 2008). Nevertheless, the participants were able to question and remain uncertain about their response, illustrating greater honesty and ability to challenge the PRs (Grundy, 1996; Kilpatrick et al., 2007). Hence, without an adult present, the use of diagnostic terminology increased the assumed severity of the experience of a psychotic episode, as the experience of post-natal depression creates the extreme imagery of individuals killing their own children mirroring media reported stereotypes of dangerous madness.

We must question the beneficial effect a medicalised dimension has on young people's psychosis literacy. In fact, trying to direct young people to engage in a discourse that involves such diagnostic labels does not necessarily reduce the moralising dimension involved in understanding the aetiology of psychosis. Instead, there is an increase in social distancing from such violent behaviour (Haslam & Kvaale, 2015), which in turn increases the perceived level of dangerousness and unpredictability associated with experiencing psychosis (Wahl, 1992; Taylor & Gunn, 1999; Jorm & Griffiths, 2008; Angermeyer & Dietrieh, 2006; Wright et al., 2011).

The level of uncertainty shown in this discussion illustrates the lack of consensus when using diagnostic terminology and, again, the dangers of utilising a biomedical model to explain what may cause psychosis. There is less awareness amongst the public about what the term 'psychosis' means compared with the term 'schizophrenia', which increases the level of anxiety and fear associated with this specific term (Addington, Berzins & Yeo, 2012). It is less likely in this context for the young person to be able to relate to such experiences, creating more danger and fear towards the possible cause of the psychotic episode. This supports the argument put forward by Fox, Buchanan-Barrow & Barrett (2008) that the use of simple diagnostic labels is not suitable when exploring children's understanding of mental illness, while the use of vignettes was more valuable in terms of allowing young people to explore the lived experience of the illnesses.

5.2.2.3 Brain abnormality or chemical imbalance.

There did exist an outlier response made during the PRFGS, which favoured a more medicalised explanation in direct disagreement with earlier possible psychological explanations of experiencing PTSD as suggested by the PRs:

> Q2: Or do you think it has to stem from a bad experience in their childhood or something like that?
> R2: No I don't think its.
> R4: No I think.
> R2: It could be due to like something wrong with the brain or something couldn't it.
> R2: hormone imbalances and like neurotransmitter imbalances in the brain

This challenge to the PR's suggestion illustrates the benefit of utilising PRs to enable peers to challenge professionally-accepted views and encourage more private opinions to generate (Grundy, 1996).

The context of such a response could credit the ability of young people to appreciate the possible biomedical underlying causes of psychosis and hence support the use of medicine. The result of putting this into a context of the individual's physical health reduced the level of stigma attached to the reasons why someone may have psychosis (Roose & John, 2003).

R2's comments could equally be discredited in terms of reducing the aetiology of psychosis as a physical health problem and not considering the wider psychological reasons for the cause of this experience. For example, during research exploring young people's understanding of mental health, Armstrong, Hill & Secker (2000) demonstrated difficulty in understanding this term, as young people either focused on being healthy in terms of their physical health or the term 'mentally' referred specifically to an illness that was not relatable.

Moreover, Fox, Buchanan-Barrow & Barrett (2008; 2010) also discredited younger children for relying on a medical model when understanding mental illness and gave more credit to older children for developing more sophisticated understanding. However, such interpretations devalue young people's attempts to relate and appreciate the causes of such experiences and should not be understood as less sophisticated, as the young people make a valid explanation supported by a biomedical model of mental illness. It appears that judgements of levels of literacy are very subjective, and dependant on what value the professional gives to each biological, psychological, or social perspective involved in the aetiology of mental illness.

The value of this outlier comment provides awareness regarding the level of dominance biomedical causes have outweighing the possible psychological arguments that existed among young people. Whereas during the ARFGS the young people were keener to engage in a balanced discussion of the potential causes of psychosis, entering the ‘good participant role’ (Nichols & Maner, 2008). Perhaps also the young people tried to avoid being perceived as simplistic, vague or wrong if they tried to provide an explanation based on possible abnormalities related to the brain, creating the ‘apprehensive participant’ which was not evident during the PRFGS (Barabasz & Barabasz, 1992).

5.2.2.4 Genetics

The desire for young people to please the AR could be interpreted during a debate young people engaged with about the possible genetic causes of psychosis:

> R: genetics like I think some people are prone to have it, but don’t necessarily have it

This view showed that R believed that genetics increased the chances of developing psychosis, but it was not a determining factor. There was no conclusive agreement that genetics was a noteworthy influence but it was a factor utilised as a debating point. The young people appeared to want to display their abilities to understand the existing nature-nurture debate, a term first coined by psychologist Francis Galton in 1883 but is still prominent in academic discussions (Galton, 1883). Hence the young people may have wanted to illustrate their academic ability to the AR, entering the ‘good participant role’ (Nichols & Maner, 2008).

The danger of such a debate led to a discussion that surrounded eugenics. This was illustrated when L questioned whether it would be appropriate for their children to marry someone with psychosis:

> L: Somebody had a mental illness and you knew it was genetic there is a chance your grandchildren could have this illness I don't know you wouldn't want that. I know I'm being judgemental.

This shows the dangers that exist if one relies on an explanation based on genetics, as the level of stigma and stereotyping has increased. This supports the medicalization dimension proposed by the folk psychiatry model, which creates the belief that psychosis is predetermined (Haslam, 2007). Hence medicalization can increase levels of pessimism, avoidance, and the belief that these individuals are dangerous and unpredictable (Haslam & Kvaale, 2015).

One must appreciate, however, that the discussion surrounding genetics occurred through direct questioning by the AR to assess the extent of social distancing the young people held towards individuals experiencing psychosis. The influence of the AR has directed and interpreted young people's responses within this biomedical framework. It is therefore important to be mindful of the influence of the power differential involved between the AR and young person in terms of what responses young people provide (Schafer & Yarwood, 2008).

In contrast, there was a lack of discussion about genetics during the PRFGS. The probable reason for this was because participants now have the chance to not feel that they needed to supply a socially-desirable scientific discussion that surrounds the causes of psychosis (Barabasz & Barabasz, 1992). Moreover, the PRs did not feel that it was relevant or important to directly explore the influence of genetic factors.

5.2.2.5 The impact of biomedical aetiology

Observations from this analysis demonstrate how influential discourse surrounding the aetiology of psychosis is shaped by expectations or agendas set by the AR. The prominence of working within a biomedical framework clearly shapes how adults determine young people's level of literacy, yet this is not considered with the same level of significance from a young person's perspective. It is important to instead acknowledge that there is no conclusive evidence on the aetiology of schizophrenia (Bentall, 2003). As professionals, we should be more open minded and less judgemental towards young people’s explanations surrounding the aetiology of psychosis.

Finally, one should be cautious about necessarily including a genetic discussion in literacy information provided to young people. The reason for this is because it generates more stigma, as supported by a systematic review which showed no compelling evidence to show that school-based literacy interventions reduced levels of stigma (Mellor, 2014). This seems to be because the interventions are adult-orientated in terms of the biomedical information provided to young people (Penn et al., 1999; 2003; Luty et al., 2007).

5.2.3 How is psychosis experienced?

Attention will now turn towards what young people thought were the key features of the experiences of psychosis. This will centre on whether the young people discussed these experiences from an emotional wellbeing perspective, or solely from a clinical symptomatic perspective. Haslam’s (2007) folk psychiatry model will be referred to demonstrate and explore this re-current theme by considering whether or not a pathological and medicalising dimension is entered. Finally the theme of whether or not individuals with psychosis were morally responsible for their actions will be addressed.

5.2.3.1 Can young people relate to the experiences of psychosis?

There is a prominent argument in the literature that has shown that the public associate mental illness with psychotic or unintelligible behaviour (Roger & Pilgrim, 2005). Secker et al. (1999) contended that if young people related to behaviour they were more familiar with, there was less chance of labelling the behaviour a mental illness. According to this hypothesis, young people in this study should be less willing to relate psychosis with their own emotional wellbeing and enter the pathologising dimension of the folk psychiatry model (Haslam, 2007).

However, as illustrated in Figure 7 below, my thematic analysis has revealed a contradictory conclusion that has shown the ability for young people to relate to the experience of psychosis, especially during the PRFGS. The consequence of this result has been a change in value determining the level of moralisation involved, and an overall challenge to the process of pathologising and medicalising the experience of psychosis:

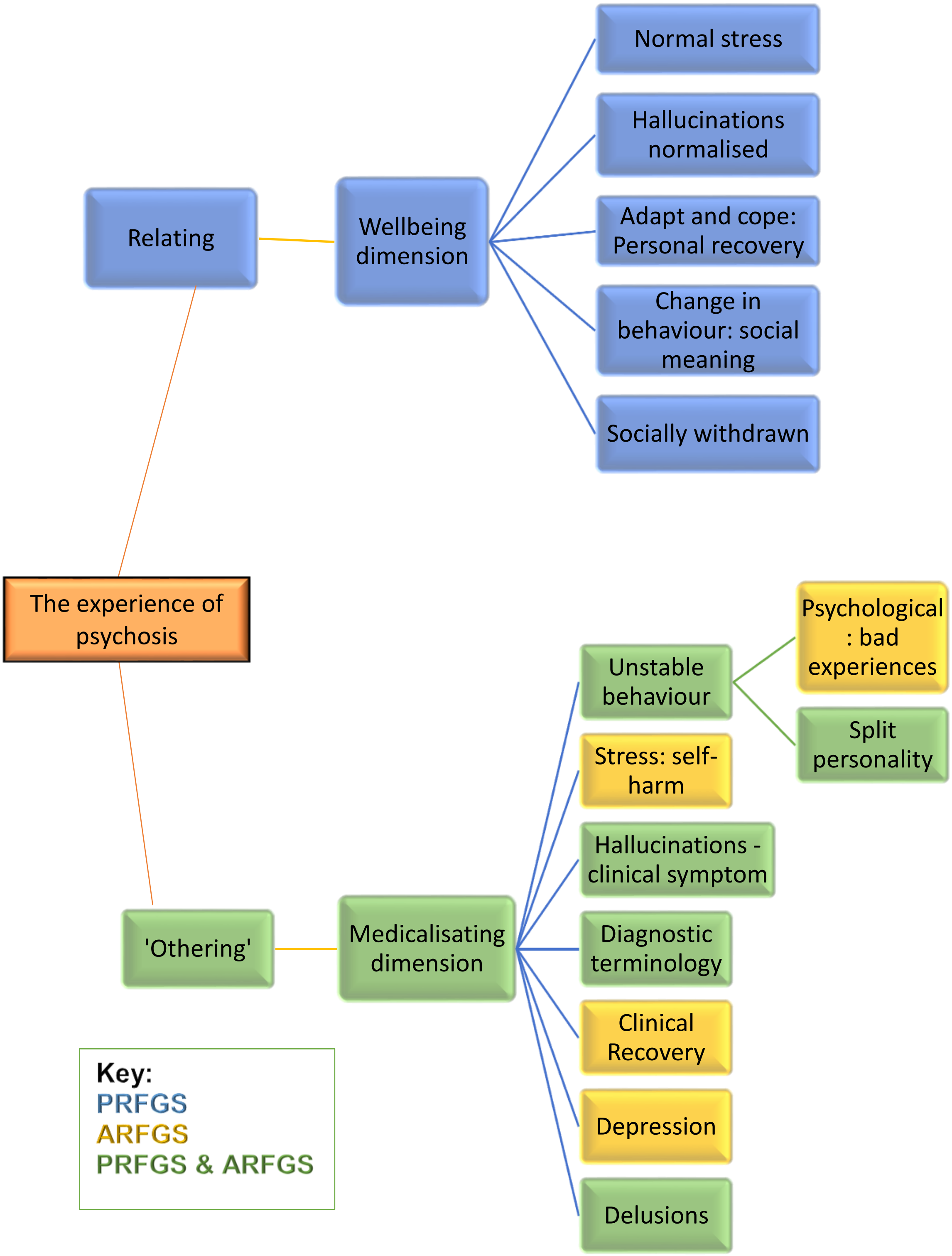


Figure 7: How is psychosis experienced?

5.2.3.2 The Pathologising, Medicalising and Moralising dimensions

The folk psychiatry model suggests that lay people’s cognition about mental illness starts through the process of pathologising (Haslam, 2007). In relation to the young people in this study, the process of pathologising was very influential during the ARFGS, but less so during the PRFGS, where there was more attempt to relate to the experiences of psychosis. This alternative dialogue questions the starting point of the folk psychiatry model (Haslam, 2007).

The medicalising dimension was consequently the stage that follows the process of pathologising in order to make sense of abnormal behaviour as being outside the control of that person and unintentional (Haslam, 2005). The dialogue agreed that individuals did not have control of their behaviour. The ability to have control over their actions was a lynchpin in making judgements as to whether the behaviour associated with psychosis was intentional or not (Haslam, 2007). The ability to control such behaviour measured and determined the extent to which young people would view such behaviour as dangerous and unpredictable (Wright et al., 2011), resulting in stigma and discrimination.

The ability of young people to relate to the experience of psychosis provided the opportunity to avoid the pathologising and medicalising dimensions usually involved. The result reduced the level of moralisation involved during the PRFGS compared with the ARFGS, which goes against the theory proposed in the mixed blessings model (Haslam & Kvaale, 2015). During the PRFGS, a social perspective placed responsibility on society for alienating, labelling, and stereotyping such behaviour within the process of social causation (Rogers & Pilgrim, 2014) and emphasised overall concern with the individual’s own emotional wellbeing and personal recovery.

5.2.3.2.1 Change in behaviour

Dialogue during the ARFGS about an individual’s change in behaviour was focused on the experience of unstable behaviour. The unstable nature of the behaviour increased the level of fear attributed to the individual’s inability to control their actions. The nature of this characteristic was pathologised as behaviour deemed as abnormal, preventing the ability to relate to the experience (Secker, Armstrong & Hill, 1999; Schukze et al., 2005). It became described within a fictional rather than lived experience context, using the analogue of Jekyll and Hyde:

> L: It's like the evil side, the Jekyll and Hyde thing it's like they are trying to make them do bad things and that thought of thing and they try and control it and remain themselves but there is that other person that is trying to tell them to do this and do that

The pathological dimension portrayed the individual's actions as appearing to be out of their control, which reduced the level of blame attributed to their behaviour. Lack of control was not caused by the individual's own decision to act in this way, as they knew it was morally wrong or bad, and they did not want to act in this manner:

> C: They haven't got control of their body sort of thing, somebody else is in there with him may be something bad that has happened in the past that is catching up with him and he feels like whatever exists suddenly he is back in the past and is catching up with him now and he still thinks it is bad and they tell him that it is bad now like his conscious

Responsibility for the individual's actions is blamed on bad past experiences catching up on him. This psychological dimension interpreted the change of behaviour as linked to the individual's bad past responsible actions. Hence, the moralising dimension is not as straightforward as the folk psychiatry model (Haslam, 2007) suggests. The behaviour may not be intentional, but it was still caused by actions the individuals were responsible for.

Nevertheless, the level of fear attached to the unpredictable nature of their behaviour still increased. This fear has been prominent in the imagery of psychosis among young people throughout the research literature (Wahl, 1992; Taylor & Gunn, 1999; Jorm & Griffiths, 2008; Angermeyer & Dietrieh, 2006; Wright et al., 2011).

There was also a link between the psychological dimension and how C related the experience of not being in control of your body to the process of medicalising the experience under the term split personality:

> C: Because they have got a split personality so in different situations, as in everybody, in different situations they behave differently so one minute they could be really nice and the other aggressive so I think it depends

The level of moralisation was reduced by using the imagery of split personality, an image normally associated with stigma and media imagery (Pinfold et al., 2005; Economou et al., 2014; 2012; Schelze & Angermeyer, 2005). The influence of the media has legitimised the portrayal of an individual having a split personality (Philo, 1996; Secker et al., 1999; Schulze & Angermeyer, 2005; Pinfold et al., 2005). The result has been the perception that the experience of psychosis has involved a personal struggle in how the individual tried to behave morally correctly but was told to act in a different manner. The level of responsibility depended on the nature of the social situation and how strong the individual was to resist such thoughts.

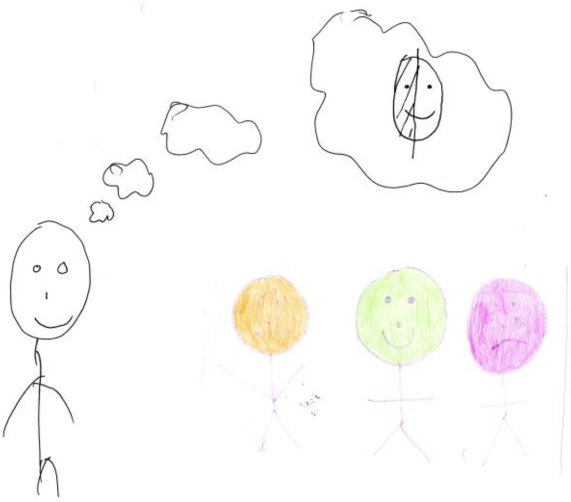
Entering a psychological dimension of understanding the experience of psychosis has given meaning to the past trauma experienced, allowing the young people to question the extent to which they are morally responsible for their actions. However, again, the level of fear attached to this unpredictable behaviour was not reduced when the young person distanced themselves from such abnormal behaviour (Schulze et al., 2003; King, 2004; Wahl, 1992; Taylor & Gunn, 1999).

Whereas, during the PRFGS, there was a more personal portrayal of the unstable nature of someone with psychosis through the lived experience of individuals, as illustrated in R4’s comment about a character called Josh from Hollyoaks:

> R4: Just that he was a really nice boy and then it turned it turned him into something horrible and he was horrible to his dad.

The personal life of Josh made the experience of being violent a relatable form of behaviour for the young person. The imagery related to the experience of having a split personality, but without the pathological and medicalised dimensions associated with this use of terminology. Instead, there was significant concern about the level of emotional turmoil involved in having a spilt personality, illustrated in two of the images drawn by the peer participants:

Drawing 1: Split personality



The emotional disturbance expressed within these images was not necessarily associated with fear or unpredictability at sudden changes of behaviour. In fact, the importance of setting up good relationships with family members and friends was emphasised as an important aspect of what the young people felt mental wellbeing meant for them (Dex & Hollingworth, 2012; Armstrong, Hill & Secker, 2000). A medicalised dialogue was avoided, increasing the chance of young people relating to the experience of having a split personality.

The comment made about the Hollyoaks character, Josh, challenges research that has blamed the media for encouraging stigma to develop among young people (Schulze et al., 2003; King, 2004; Wahl, 1992; Taylor & Gunn, 1999). One needs to re-evaluate the influence of media, as it appears that this research may be outdated, and has not taken on board a change in the media’s role to portray mental illness accurately. This supports the potential benefits of media involvement in the development of young people’s mental health literacy (Scott & Chur-Hansen, 2008). For example, the 15-minute video ‘The Same or Not the Same’ avoided the first step of pathologising by creating the opportunity for young people to relate rather than distance themselves from someone with schizophrenia (Chan et al., 2008).

There was a similar reaction made by R2, who did not pathologise the change of personality that she noticed with someone that she knew personally:

> R2: It was different seeing their different side of the personality because I was used to seeing them being different and these people were quite

> confident in a person themselves, and then they started to go a bit crazy. So it wasn't nice.

As the dimension of pathologising decreased, more concerns became centred on the individual's lived experience of psychosis. This supports the theory that when the experience was more familiar for young people, there was more ability for young people to relate and identify with the experience, decreasing its pathological nature (Schulze et al., 2003; Seker, Armstrong & Hill, 1999).

The effect of personal contact with an individual clearly influenced the understanding and portrayal of changes in behaviour associated with psychosis. This supports the findings of Secker et al. (1999), where there was a notable lack of sympathy related to the adult vignette compared with the young person vignette. This was because the young person character in the vignette was less likely to be perceived as having a mental illness and was instead understood and normalised with the common belief of having monsters under your bed.

Exposure to more personal experience and a dialogue orientated towards understanding the lived experience of psychosis has enabled young people to relate to the nature of the change of behaviour during a psychotic episode. Whereas, dialogue orientated towards explaining the change of behaviour within a pathologizing dimension limited a moral judgement towards their behaviour, but increased the level of fear and social distance, supporting the mixed blessings model (Haslam & Kvaale, 2015).

During both ARFGS and PRFGS there was a significant amount of questioning on what level of responsibility individuals had over their psychotic behaviour. R4, for example, discussed his rationale why he did not think it was right to have contact with a young person who was experiencing psychosis. The preference for an adult service user was safer in terms of potential erratic behavioural change that may result from a young person:

> R4: I would rather have an adult because do you know with a young person, they haven't got much control…They don't know the right or the wrongs really would they?

This statement made by R4 goes against earlier research findings that young people would be able to be more sympathetic towards a young person experiencing psychosis (Secker, Armstrong & Hill, 1999). However, the reason for R4’s comments actually highlights the impact that a specific diagnosis changes the level of morality attached to the young person’s behaviour. In contrast, Secker, Armstrong & Hill (1999) utilised a vignette without a specific diagnosis, which enabled the young people to not label the behaviour as psychotic. The difference that a diagnostic label can make on the level of moralisation appears to confirm the anxieties present in MHL interventions which have avoided using the diagnostic label of psychosis or schizophrenia (Pitre et al., 2007; Penn et al., 1994). The result is that there is less sympathy and more blame attributed to the young person for not having much control.

R4’s comments support research highlighting boys’ less benevolent attitude, and greater estimation of danger posed by the individual’s change of behaviour (Leong & Zachar, 1999). The gender difference during the PRFGS resulted in an increased level of moralisation attached to the behaviour (Jorm & Wright, 2008; Williams & Pow, 2007; Burns & Rapee, 2006). The PRFGS recruitment allowed a greater exploration of male-orientated social interaction when exploring the experience of psychosis (Monahan & Fisher, 2010).

5.2.3.2.2 The experience of stress

During the ARFGS, stress experienced associated with psychosis was perceived to be more abnormal and extreme than normal day-to-day stress experiences. This pathologising framework increased the level of concern and fear shown towards the unpredictable nature of their behaviour:

> B: I put 3 as well I just think like I would be dead worried in case he did get stressed looking after children and he might just decide to walk out the house and leave them

The risks associated with this level of stress prevented occupational activity and created the possibility of causing harm to themselves. The context of B’s response was in relation to the AR asking whether they would be comfortable asking someone with psychosis to babysit their children. This question led the young people to respond emotively in defence and concern for their children, automatically thinking of the worst-case scenario. The only known information about the babysitter was their label of being psychotic.

There was also more concern directed at the risks surrounding the needs of these individuals due to the experience of stress. M, for example, expressed concerns surrounding possible self-harming behaviour. C also felt that the prospect of having psychosis could make young people feel suicidal and lack hope in their lives:

> M: may affect you by causing harm to yourself
> C: You imagine people thinking that I'm not going to get better I'm not going to get better and you imagine how probably be suicides

Hence, the experience of stress in a pathologised and medicalised framework had grave consequences. The adult professional possibly influenced the use of such clinical language, which prevented shared common language used in relation to the experience of stress (Kirby, 1999). The power differential between an adult and young person directed the orientation of medicalisation (Schafer & Yarwood, 2008). It thus conformed to an adult-focused deficit framework in protecting young people from such worries and anxieties expressed by C (Morgan & Ziglio, 2007).

In contrast, the term 'stress' was a less pathology-driven term during the PRFGS. R3 used the term 'stress' in a casual manner that had no indicator that it could potentially cause psychosis. The young people disagreed that you could assume that being stressed or angry could be used to identify who had psychosis when shown images of individuals – two whom displayed angry emotions:

Image 2: Angry individuals

> R3: I mean they're both angry, but you can't say that's because they have schizophrenia, you could just be stressed with exams or something.

The resistance to diagnose individuals challenges the concept of literacy, which involves the criterion of having the ability to apply a diagnosis (Read et al., 2006), which in this case was inappropriate and stereotypical. Young people have avoided the use of stereotypical language and challenged a pathological understanding of stress.

R3 demonstrated the shared meaning and experience of stress caused by exam pressure (Kirby, 1999). This allowed the young people to relate to the experience, avoiding the pathologising dimension within the folk psychiatry model (Haslam, 2007).

5.2.3.2.3 Withdrawal

The process in which individuals with psychosis were described as withdrawn stems from a context in which the young people attempted to relate to the lived experience of having psychosis:

> B: lock themselves away, like if they don't want to see anyone
> E: you are withdrawn and like I don't know you separate yourself off because you are feeling alone and that anyway
> A: right good, you have put quiet, shy, lonely they seem to be quiet, why do you think that
> H: I don't know people don't share their thoughts and feelings with others they don't talk about it and it would make you lonely

The young people felt there was a degree of personal responsibility for individuals to seek support and share their feelings. It was the failure of not receiving this level of integration with society that led to the process of withdrawal. A wellbeing perspective, rather than pathological or medicalised framework, increased the moralisation of the behaviour, but created the feeling of responsibility to support these individuals.

Moralising behaviour does not necessarily entail the process of blame or stigma, but can empower these individuals to make a choice in their behaviour and gives individuals the opportunity to seek self-help strategies. From a professional perspective, these self-help strategies have often been labelled as inappropriate (Jorm et al., 2008; Lauber et al., 2001; Kermode et al., 2009). The young people however felt it was important for these individuals to engage in their community as a form of recovery.

L and Sh also pointed to another reason withdrawal may occur, which was based on the attitude of others making these individuals feel that there is no other choice but to behave in such a manner:

> L: I think they would be quite lonely and scared to tell other people what they have…separating themselves from everything…if they weren't ever playing with other kids they were the only one, would be treated different when they grow up
> Sh: feel singled out
> C: it's like solitary confinement
> B: being isolated from their family and friends

The lack of society's ability to relate to psychotic experience has been blamed for creating withdrawal. This anti-stigma stance has illustrated the problem with entering a pathological and medicalised dimension. The implication is that it is not up to the individual to try and integrate with their community, but it should be the community's role to ensure these individuals do not become withdrawn. The resultant lack of moralisation can help individuals receive the necessary support needed, as there is a greater likelihood to seek professional help if suggested by their peers (Cusack et al., 2004).

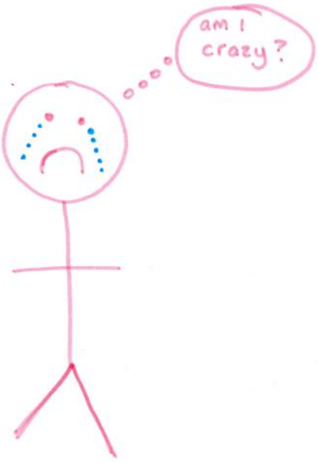
This viewpoint continues to become a more prominent explanation during the PRFGS. This explanation was based on being homeless, and personal feelings attached to the process of being diagnosed with ADHD, which was related to how it must feel to be diagnosed with psychosis:

> R1: I would say just because homeless people see even talking to themselves doesn't mean they necessarily have schizophrenia or a mental disorder its just because they're quite withdrawn from society and because of the position they're in they may even blame society for it so.
> R1: I was frankly left out in the cold in many social situations.
> Q2: What do you mean out in the cold?
> R1: Just left alone almost, ignore me, no one would.

The consequence of reducing moralisation enabled young people to relate to and empathise with the reasons why someone may become withdrawn from society. This supports findings from Secker et al. (1999) where less sympathy was given to an adult compared to a young person because the young person's experiences were less likely to be labelled as a mental illness. More focus was given to the young person's personal experience.

One of the drawings made by a peer participant summarised the isolating feeling that one may experience if they were treated as being crazy:

Drawing 2: Am I crazy?



The social meaning attached to the experience of being diagnosed with a mental illness should not be neglected when considering the emotional wellbeing dimension of experiencing this illness (Coombes et al., 2013; Brooks & Magnusson, 2006). Focusing on literacy requirements that place a high value on the ability to identify and apply a diagnosis (Read et al, 2006; Spitzer & Cameron, 1995) can result in a negative moralising effect and the danger of not catering or responding appropriately to young people's literacy needs.

5.2.3.2.4 Diagnostic terminology

The process of medicalising involved young people debating subjects surrounding the different diagnostic terminology involved when discussing psychosis. This level of debate illustrated the level of confusion and importance to distinguish, explain and understand the meaning of different diagnostic terms:

> L: That's bipolar. Bipolar is the one that's like when there are two different personalities. Isn't schizophrenia like imagining that someone is talking to them or something? I think that is schizophrenia
> C: isn't there something to do with schizophrenia don't know whether that's got to do with psychosis schizophrenia.

This dialogue reflects the level of importance attached in the ability for young people to identify, label and diagnose specific mental illnesses to determine literacy (Wright, Jorm & Macknnon, 2012; Wright et al., 2006). Hence, as the adult researcher was conducting the research, there was an agenda to specifically choose to focus on the term psychosis instead of the more specific diagnostic term of schizophrenia. This created an expectation that the young people would debate this. However there were perhaps inappropriately increased levels of apprehension and fear surrounding their lack of understanding of the meaning surrounding the term psychosis in comparison with the term schizophrenia (Addington, Berzins & Yeo, 2012).

The consequence was that there were more expectations and demand characteristics placed on the young people to orientate their discussion through an explanation of diagnostic terminology (Barabasz & Barabasz, 1992; Nichols & Maner, 2008). The dominance of using diagnostic terms continued to be relevant during the PRFGS, where the PRs were keen to prove to their peers their superior knowledge and understanding of these diagnostic terms:

> Q2: Psychosis is a term used to describe a combination of symptoms including delusion, unshakable belief that an untrue e.g. plot or to harm or be taken over by aliens.
> Q: Yeah it's true. It can also be stress or symptoms of schizophrenia, bipolar disorder, Schizoaffective Disorder, dementia, some forms of personality disorder, Parkinson's, drug and alcohol abuse, drug-induced psychosis, and side effects of some types of medication.

The PRs felt that it was important to clarify the diagnostic language used to inform/teach their fellow peers as the more outgoing and articulate volunteer PRs (Bland & Atweh, 2007; Kirby, 1999). The potential influence of the PR on the participants was the possibility of being unable to distance themselves from the topic and allow the participants themselves to explore the meaning of these diagnostic terms (Jones, 2004).

Nevertheless, this dialogue does show the dominance of an adult/professional-orientated perspective on what was important when advocating psychosis literacy interventions for young people. This reflects the previous emphasis made in MHL interventions that have attempted to demythologise or identify schizophrenia (Chan et al., 2009; Wright et al., 2006). The conviction in the factual nature of providing biomedical information remains very influential, and has driven professional attempts to reduce perceived illiteracy of young people (Bailey, 1999; Rose et al., 2007; Nisha et al., 2005) to prevent young people from excluding their peers with a mental illness (Kirkaldy, Eyserck & Siefan, 2004; Hayward & Bright, 1997).

There is no concrete evidence to illustrate the actual benefits of embedding literacy within a biomedical framework to reduce stigma (Penn et al., 1994; 1999; 2003; Mellor, 2014; Luty et al., 2007). Potential problems instead originated from using such diagnostic terms during the PRFGS, where R1 attempted to determine the differences between psychosis and schizophrenia:

> R1: isn't psychosis short-term and schizophrenia involve like having a split personality?

Consequently, the diagnosis of having schizophrenia became more severe and permanent than experiencing an episode of psychosis, which may only involve a short psychotic episode. Schizophrenia was associated with a change of personality. This reflects how R1 wanted to know the differences involved in specific diagnostic terminology, supporting findings showing greater public awareness of the term schizophrenia than psychosis (Addington, Berzins & Yeo, 2012). This increased the request for further information to make a distinction between the different diagnoses (Williams & Pow, 2007; Woolfston et al., 2008).

The result of this attempt to distinguish a diagnostic criterion created the feeling that recovery was difficult. This is because the perception of having a split personality was that it is something that is severe, which reflects many MHL interventions that have purposefully contrasted schizophrenia with other mental illnesses in order to support their hypothesis that stigma will increase as a result of the level of severity associated with schizophrenia (Conrad et al., 2009; Sakellari et al., 2014; Pinfold et al., 2003; Rickwood et al., 2012). There is an assumption that schizophrenia will be stigmatised, as it is associated with having a split personality.

5.2.3.2.5 Recovery

The concept of recovery has become widely applied within mental health systems, and exists with different meanings, from clinical recovery (an objective judgement made by clinicians) to personal recovery (subjective continuum defined by the individual) and more recently from a critical perspective when considering the genre of Narrative Recovery (Woods, Hart & Spandler, 2019; Slade, 2009). When the concept of recovery was explored clinically by the young people in this research, there was less ability to relate to these clinical symptoms. However, personal recovery was orientated within a dialogue that enabled the young people to relate to the lived experiences of psychosis. A comparison of these contexts will be explored in this section.

Discussions surrounding the ability to recover contrasts the level of stigma that often accompanies the perception that once someone has schizophrenia their prognosis is poor and recovery is not possible.

There was certainly overall significant debate whether recovery was possible during the ARFGS. On the one side of the argument total recovery was not considered likely, and instead coping with the condition was a more realistic outcome:

> E: you might not fully recover from it but it will improve like they will be able to go back to do normal daily things
> E: I don't think that you can recover like they can just get used to it and live with it

This side of the argument fits within the medicalised meaning of clinical recovery. The reason used by the young people to support this argument was the fact that there were potential triggers that could set off another psychotic episode at any time:

> C: I think that it can be controlled but I don't think recover as it could come back. Like if something happened that unsettled you or like change a turning point in life something like that it could come back
> L: I don't think it can go away whatever causes you to have it in the first place would happen again or something could trigger could happen again yeah but I think it could be controlled unless it's really severe

The influence of these triggers illustrated the feeling that recovery was determined on whether or not the individuals were able to control the onset of any psychotic behaviour. The level of concern surrounding the ability of individuals to control their behaviour increased levels of fear associated with the level of behaviour that is dangerous and unpredictable (Wright et al., 2011). Clinical recovery has not reduced the level of moralising associated with the experiences, as hypothesised in the mixed blessings model (Haslam & Kvaale, 2015). This is because the nature of these triggers was something that the individual could potentially control and plan for, placing more responsibility to control these triggers to ensure that recovery is a possible goal.

C and L both expressed thoughts that psychotic behaviour could be controlled through medical intervention. The young people did not believe that the medicalisation dimension necessarily meant that it was outside of the individual's control, as suggested by the folk psychiatry model (Haslam, 2007). Moreover, young people discussed the importance of personal recovery, defined in relation to the individual's personal circumstances:

> L: suppose like you might get people in which nothing works for them and they might always have
> C: if you have medication and stuff it's going to calm it down a little bit but it's not going to completely get rid of it
> Sh: I think the individual wouldn't need help to recover it but it's more up to them to recover from it if you know what I mean they have to solve it themselves kind of thing
> H: if there is a specific thing that is causing it and that was resolved then they might not have schizophrenia again

These comments place more responsibility on everyone to find what works for them to enable possible recovery. For example, Sh placed more responsibility on the individual to be able to solve their issues independently. Professionals were not the only experts involved in recovery. The level of importance given to service user involvement is a credible and ongoing target within mental health services as acknowledged by the young people (Grundy et al., 2016; Slade et al., 2014; Grant et al., 2015).

MHL interventions have traditionally focused on promoting correct help-seeking behaviour, and this has been an area young people have been criticised for in terms of suggesting inappropriate self-help approaches for psychosis (Jorm et al., 2008; Lauber et al., 2001; Kermode et al., 2009). The context in which these young people have suggested the use of self-help for the process of recovery shows the benefits of not necessarily focusing on a medicalised notion of what is best for the service user. Therefore, when young people have expressed their negative and resistant attitudes towards the use of psychotropic medication, one should explore further what the reasons for this might be within the context of personal recovery (Angermeyer & Matschreger, 1996; Jorm et al., 1998; Priest et al., 1996).

Focus on clinical recovery had the effect of young people not being able to see the possibility of recovery, as shown when M used a diagnostic criterion to compare the diagnosis of schizophrenia with depression:

> M: The way the teachers talk about it stereotype didn't say any other point like they didn't say any positive thing like how they say people with depression would live a normal life but schizophrenia no one says or you can still live a normal life they just assume they are not going to like have one
> A: so would you class this type of illness of psychosis as one of the more severe types of mental health conditions compared with depression
> M: Like depression is really common and like depression doesn't have to stay forever people get over depression but like mental health illness like it's almost impossible to get rid of it, like you can get better but you can't get rid of it

This comparison between different mental illnesses illustrated that the medicalisation of schizophrenia created a belief that the individual was not in control of their future. It created a disempowering effect on the individual and a bleak destiny for the prospect of recovery. The result of this labelling process is in direct contrast to the benefits perceived in the aims of MHL interventions to improve the ability of young people to provide labels in order to reduce the perception that individuals are weak and not sick, so that help-seeking is increased (Wright, Jorm & Macknnon, 2012).

The need to focus on diagnostic labelling to enable recovery requires consideration, as the rationale which supports the need for labelling is based on the premise that recovery is dependent on gaining the right and appropriate professional help and support (Secker, Armstrong & Hill, 1999; Kelly, Jorm & Wright, 2007; Sakellari et al., 2011). In contrast, for young people during the ARFGS, the meaning of recovery involved considering the psychological wellbeing of the individual, which opens the doors towards considering more psychological sources of help.

In comparison, during the PRFGS, the term recovery was missing. This could be an indicator that the need to appear optimistic and anti-stigmatising was not as expected or as strong when discussing this topic with their peers (Nichols &

Maner, 2008; Barabasz & Barabasz, 1992). More colloquial terms of adapting and coping with the condition replaced the term recovery, illustrating more shared local common language than language dominated by a medicalised concept of recovery (Kirby, 1999):

> R2: I think after you've got used to it, adapt to it, learn to deal with the condition
> R4: Adapt to it, but after a while.
> R4: It depends, it's one of those things, I think you don't live the same life as somebody who would if they didn't have it. It doesn't necessarily affect your life in a bad way

Understanding the meaning of personal recovery has increased understanding how one can cope with the lived experience of psychosis. The determining factor from R2 and R4's perspective was how the experiences were individualised, and dependant on the ability of how that individual was able to adapt or learn to cope within their own environment.

This has informed the importance attached to personal recovery in contrast with clinical recovery in future literacy initiatives provided to young people. This supports the argument that we need to listen to young people's expressed health educational needs and avoid providing information that is perceived as most appropriate without real meaning or value for the young people (Tones, Tilford & Robinson, 1990; Schafer & Yarwood, 2008).

The consequence of avoiding a clinical recovery interpretation is that it has not resulted in any increase in blame directed at these individuals, as suggested in the moralising dimension of the folk psychiatry model (Haslam, 2007). Next, we shall examine how the young people tried to explain the clinical symptoms of psychosis, focusing on the symptoms of depression, hallucinations and delusions, and whether or not these fit into a medicalising dimension of understanding psychosis (Haslam, 2007).

5.2.3.2.6 Depression

During the ARFGS, the experience of having depression and developing psychosis was connected in terms of how the symptoms may present and become a possible cause of developing psychosis:

> H: I think it's from depression you are not mentally stable so your mind sort of messed
> C: some people might just have depression and they could say feel that they are getting psychosis or have psychosis but they don't they could just be at a low point in their life of depression and they wouldn't go because they know in their head that they are depressed and not experiencing symptoms so they wouldn't go because at the end of the day psychosis depression is a form of psychosis

Medicalising the experience of psychosis as a form of depression led to the young people justifying how this experience was involuntary and why receiving medical help was important. The interpretation of such diagnostic language conformed to a professionally acceptable response (Barabasz & Barabasz, 1992; Nichols & Maner, 2008). This is an important observation in terms of the manner in which social interaction has influenced and produced dialogue interlinking the experience of depression with psychosis (Monahan & Fisher, 2010).

The young people were consciously aware that from a professional perspective being literate was centred on the ability to improve diagnosis and facilitate early help-seeking behaviour (Secker, Armstrong & Hill, 1999; Kelly, Jorm & Wright, 2007; Sakellari et al., 2011). Therefore, the young people felt that linking depression with psychosis would help the process of individuals seeking appropriate professional help and support. This supports findings that have shown the negative imagery of schizophrenia compared with depression or PTSD (Amanas, 2008; Angermayer et al., 2004).

However, during the PRFGS there was a lack of linking with the experiences of depression and psychosis. The only comment made on clinical depression was during a true or false activity where the young people were directed towards asking whether symptoms of psychosis would occur after pregnancy, severe depression, or sleep depression:

> R2: True because you get postnatal depression. Postnatal depression like in some severe cases people actually kill their children

The power differential between PR and participants has not been entirely removed (Schafer & Yarwood, 2008; Murray, 2006). The influence of the AR's agenda is still prominent in utilising a diagnostic framework to discuss the symptoms of psychosis. There was no naturally occurring dialogue that connected psychosis with depression. The link to post-natal depression was illustrated to show the dramatic consequences of the actions of these individuals, and how they can significantly change their lives as a result of these actions. This further supports the importance of exploring and acknowledging the influence of social interaction on young people's responses.

The experience of being sad, rather than being depressed, was a feature that appeared more common in the focus group dialogue between peers:

> R4: It can involve feelings of being sad
> R1: obviously be sad because they have trouble with their lives
> R5: I drew its just a person who's upset because they've got voices going on in their head and they don't understand why its happening

This example of more colloquial terminology again confirms the influence that PRs had to explore shared common language when discussing the experiences of psychosis (Kirby, 1999). This then fostered a discourse framed within a biomedical explanation. The lived experience of having voices or facing troubles was the main source of sadness. The experience of having voices was couched within concerns for the individual's mental health wellbeing. The young people tried to relate what these experiences must have felt like to the individual, an aspect neglected when using the term 'depression'.

Avoiding a medicalising interpretation of the symptoms of psychosis has increased the ability of young people to relate to the experiences of hearing voices (Seker, Armstrong & Hill, 1999). This had the same effect during the ARFGS when discussing the lived experiences of psychosis:

> L: be sad as well because like you felt that you are the only one
> Sa: They are feeling low and that, frustrated, feeling down

The sociological understanding of the reasons why experiences of sadness may occur is an area that requires further exploration in terms of catering for young people's literacy needs. It appears to be a potential area that has been neglected in previous health literacy interventions, as adult professional conceptions do not necessarily mirror a young person's construction of their literacy needs (Sixsmith et al., 2007; Coombes et al., 2013; Schafer & Yarwood, 2008; Tones, Tilford & Robinson, 1990; O'Reilly et al., 2013).

The four-dimensions suggested in Haslam's (2007) folk psychiatry model do not cater to young people's ability to relate to the emotional wellbeing experiences associated with psychosis. It is therefore important to be aware of the ways in which diagnostic terminology can alter the dialogue young people engage in when understanding the experience of psychosis. Focus will now turn towards the term hallucinations.

5.2.3.2.7 Hallucinations

The experience of hearing voices was one of the main clinical symptoms associated by the young people with psychosis. However, it was during the ARFGS that there was more emphasis placed on the importance of naming the symptom of hallucination to pathologise the illness:

> B: talking in two different voices like he was two different people but they were completely different and when he was that nasty person his eyes were just rolling about, rolling back and stuff
> Sh: They might be talking to themselves like quietly in the corner
> C: you kind of be able to tell by them talking to themselves and stuff

This imagery enabled identification and diagnosis within a medicalised dimension. The effect however increased the level of fear and social distancing associated with the experience of hallucinations. B's response was in relation to watching Channel 4's '999: What's Your Emergency?' documentary. Wahl (2003) and Wilson et al. (2000) agree that the media has been responsible for depicting the imagery of psychosis as unattractive, violent, and criminal in nature.

During the ARFGS responses demonstrated more shock and horror towards the violent and aggressive actions of these individuals. The experience of voices depersonalised the individual's actions and did not consider moral responsibility.

> L: he heard the voices and it made him do sort of really dramatic things I didn't ever before think it could make someone start a fight possibly
> H: I did it at GCSE History which was a massacre with schizophrenia and said that the voices in his head would tell him to kill people at school because they hated him and were horrible to him and stuff like that.

The focus on the symptoms of voices made the experience less familiar, and therefore more dangerous and unpredictable, but also made people less morally responsible for their actions. Experiencing a hallucination was described as an alternative world, creating abnormal perceptions for these individuals:

> L: Warped view of reality. Imagining things that sort of thing
> C: living in an imaginary world rather than the realistic world. Looks like they are spinning sort of thing just not seeing the world from someone else would it’s going really fast
> L: It could be things that aren’t there or that things could be blurry
> C: Imagine situations that aren’t really there

Medicalising the experience of hallucinating created a significant amount of social distancing within this experience. The symptom of hallucinations made the young people feel frightened of the possible consequences of the violence and aggression that may arise from their actions:

> L: he heard the voices and it made him do sort of really dramatic things I didn’t ever before think it could make someone start a fight possible
> H: I did it at GCSE History which was a massacre with schizophrenia and said that the voices in his head would tell him to kill people at school because they hated him and were horrible to him and stuff like that.

The consequence of these findings has often been caution or avoidance of focusing on psychosis as an appropriate topic for young people. This is because it was not perceived to be as relevant or related to young people’s own mental wellbeing needs and only increased levels of stigma attached to mental illness (Howard et al., 2008; Naylor et al., 2009; Saporito et al., 2011; Schulze et al., 2003).

This finding supports the mixed blessings model’s caution in utilising a diagnostic framework (Haslam & Kvaale, 2015). The experience of hallucinations was a characteristic that one could not relate to. The social meanings attributed to the experience of hearing voices has therefore been neglecting within this clinical diagnosis. Similarly, social meaning has also been neglected in the literature across different health subject areas when exploring young people’s emotional wellbeing (Brooks & Magnusson, 2006; Coombes et al., 2013).

Similarly, during the PRFGS, young people related violent behaviour to the experience of hallucinating. The difference was that discourse visually depicted a frightening and dangerous hallucinating experience related to media imagery.

> Q: Right and do you think that was portrayed accurately?
> R1: Yeah she imagined that there was some sort of cat or rat that was telling her to try and kill her parents. Yes, it was disturbing.
> R1: she thought that there was a little baby at the end of her bed when there wasn't.

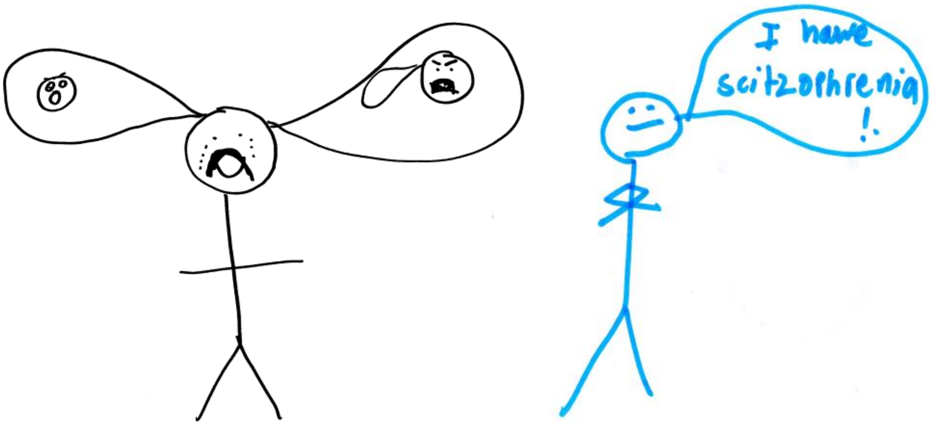
This form of imagery related to the experience of hallucinations within personal documentary stories. The media's use of diagnostic labelling has increased the level of social distancing by creating the feeling of being dangerous and unpredictable (Jorm & Griffiths, 2008; Angermeyer & Dietrich, 2006; Wright et al., 2011). However, it did not directly blame the individual's behaviour, but expressed concern regarding the severity of how psychosis may affect their behaviour.

There was more confidence in the young people's responses to not provide sugar coated answers, an advantage noted in the use of PRs (Burns & Schubotz, 2009). This indicates that in the ARFGS the young people were more reserved in how they expressed their concerns, avoiding the process of moralisation.

One of the main differences noticed during the PRFGS was the likelihood to associate the experience of hallucinations with the context of emotional wellbeing. This link reduced the level of moralisation, as concern did not focus on the bad behaviour that resulted from the hallucinations, but instead on how the experience of hallucinations made the individuals sad or upset. R1, R2 and R3 all commented on this negative experience when asked to draw someone experiencing a psychotic experience:

> Q: And why have you drawn him sad?
> R1: Well a lot of people find that they have voices in their head or characters around them but a schizophrenic can't tell the difference so would obviously be sad because they have trouble with their lives
> R2: I drew its just a person who's upset because they've got voices going on in their head and they don't understand why its happening and they
> R5: Because she's unhappy and she's got her hands in her on her head as if she's like as if there are voices going on inside of her head
> R3: He's got his arms folded because he's pissed off with having two voices in his head and he's got a straight face because if you've got one voice that is happy and one that's sad it'll balance out with a straight face.

Drawing 3: Experiencing hallucinations



This level of concern emphasised the fact that these individuals were understood as the victims of their voices. They were not in control or responsible for their experiences. Hence, personalisation of experiencing hallucinations helped decrease moralising judgements held about the level of accountability for their actions. In contrast, a depersonalised medicalising focus on the symptoms of hearing voices may attribute more moral responsibility to their violent actions, increasing the level of stigma attached to this experience (Secker, Armstrong & Hill, 1999; Schulze et al., 2005).

The PRFGS allowed the young people to direct their dialogue away from a pathologising dimension. R1 disagreed that the experience of having voices in your head was a distinctive characteristic for diagnosis of schizophrenia:

> R1: Well a lot of people find that they have voices in their head or characters around them but a schizophrenic can’t tell the difference

R1 felt instead that the experience of having voices in your head was an experience held with wider and relatable connotation. The experience entered the emotional wellbeing arena and was not just hemmed within psychiatry. R1 only distinguished this experience as a mental illness if the individual was not able to tell the difference between what is real and what is not.

This challenge against pathologising showed the potential benefit of utilising PRs to challenge the dominance of psychiatry in dialogue and supplying an alternative interpretation, which may stem from more privately held views (Grundy, 1996). The theme of challenging the medicalization of hallucinations continued when R1 challenged this symptom among the homeless when related to these individuals' first-hand experiences:

> R1: I would say just because homeless people see even talking to themselves doesn't mean they necessarily have schizophrenia or a mental disorder its just because they're quite withdrawn from society and because of the position they're in they may even blame society for it so

The lay understanding of experiencing hallucinations does not necessarily enter the first process of being pathologised (Haslam, 2007). There was a greater concern related to the impact that stereotyping and stigma would have on the individual's life. In the case of the homeless person, the process of talking to yourself was seen as a solution to loneliness and withdrawal from society. It was rational behaviour, and not within the realms of psychiatry.

The social imagery of being homeless was significant for R1 when considering who may have psychosis. R1 blamed how society reacted towards these individuals and dismissed the experience of talking to yourself as a reason for labelling someone with psychosis. R1 recognised the dangers of pathologising experiences without considering the whole lived experience of psychosis. The effect was that such an approach prevented consideration of looking at the mental health wellbeing perspective of these experiences:

> R1: talking to yourself can be one thing even just having a sort of imaginary characters

These views support the importance attached to avoiding misinterpretation of the symptoms of psychosis related to the normal experience of childhood. Ecclestone & Hayes (2009a; 2009b) supported this argument in terms of expressing the need to be cautious in creating vulnerable young people through self-diagnosis. R1 went on to show personally that she talked to herself all the time, and feels that such actions are socially acceptable:

> R1: I talk to myself all the time no joke and because I like it doesn't necessarily mean I have schizophrenia.

These statements, all made by R1, illustrate how it is possible for young people to understand and appreciate the social and psychological context of an individual’s experience without necessarily pathologising the experience. The symptom of talking to oneself was an intentional act within the context of normal dialogue young people had with their own thoughts. Hence, the pathologising dimension suggested by the folk psychiatry model was not applicable (Haslam, 2007).

Young people’s failure or illiteracy to medicalise or pathologise the experience of hearing voices was discredited in Wright et al. (2006) when young people were not able to identify psychosis in a vignette. The social meaning attributed to the experience of hearing voices can be beneficial in reducing the level of social distancing. This supports the notion that young people are more reluctant to label experiences as a mental illness when they can relate to this experience (Secker, Armstrong & Hill, 1999). Thus, their experience belongs within the mental wellbeing rather than illness perspective (Potts, Gilles & Wood, 2001).

On the other hand, the inability to pathologise or medicalise the experience could be a form of avoidance to engage in a dialogue focused specifically on mental illnesses. This avoidance has been a common theme within schools’ preferences to focus on positive mental health or emotional health wellbeing (Armstrong, Hill & Secker, 2000; Kidger et al., 2009). Wright et al. (2011), for example, argued that there was no benefit in using the term schizophrenia when trying to reduce stigma. This level of avoidance does not address the need to break the taboo associated with the terms psychosis or schizophrenia to help decrease levels of stigma and discrimination. Nevertheless, lessons should be learned on how literacy interventions should not prevent, or discredit, discourse engaged about the social meaning of hearing voices.

The difference in response from the PRFGS compared with the ARFGS could possibly stem from the fact that the young people were less engaged in an academically-directed discourse, taking the role of the good participant role (Nichols & Maner, 2008). This has allowed young people the opportunity to not enter the pathological dimension. These results are contrary to research that has demonstrated how young people were more likely to focus on mental illness and equate mental wellbeing as mental illness (Nadzeya, Bone & Dogra, 2014; Dex & Hollingworth, 2012; Shucksmith et al., 2009).

To further support this point, there was even criticism within the ARFGS that the provision of any proposed psychosis literacy should further explore the meaning and experience related to hearing voices:

> H: I think in Health and Social we touched on it a little bit people seem to rush into that you know what it is and you don't it's like they will say schizophrenia and just jump to that it's hearing voices and stuff and no one really explains what it is

Young people during the ARFGS were also concerned about the emotional wellbeing experience of these individuals, and how it may affect the individual's daily routine:

> M: may lack what an ordinary person's routine would be like if they hear voices…Like if you were hearing voices or you were hallucinating then you might see people that aren't there and then if you are hallucinating then something might happen and you might separate yourself from other people and then bad things will happen
> L: different voices that could be telling you things that make you feel nervous and now I don't know how it would be to have voices in my head but you may think other people may hear them or if it was diagnosed you might feel more paranoid about it because other people may see it more if it was undiagnosed you might not even know they are in your head you might just think they are sort of there they are real voices might get distracted might think they are real people shouting and distracting and a bit lost I think to hear voices in your head you must be a bit lost to have like to have a mental being people tell you things and feel like a lost person I don't know that's what I thought

This explanation reduced the medicalising dimension of understanding the experience of hallucinating. In return, young people were given more opportunity to understand the emotional impact hallucinations had on the individuals' lives.

The benefits of focusing on young people's emotional wellbeing were highlighted in young people's suggestions to further explore the emotional and positive social meaning attached to sex and relationship education. Young people expressed in Ellis, Pararani & Fauth (2009) that the lived experience of real couples and real-life stories had been neglected. Instead, a focus on a biomedical explanation of sex, or an adult deficit framework on risky behaviour (Morgan & Ziglio, 2007), had neglected young people's sex education.

It is therefore important to appreciate the type of information young people need about specific mental illnesses such as schizophrenia (Williams & Pow, 2007). There are potential problems in the application of explaining psychosis through a factual diagnostic criterion as this will neglect how young people construct their explanation of the experience of hearing voices (Sixsmith et al., 2007). Nevertheless, young people did pathologise psychotic behaviour, and the result involved young people making a judgement whether the individuals were personally responsible for their actions.

5.2.3.2.8 Delusional thoughts

The clinical symptoms of delusional thoughts were considered an experience that the young people were unable to relate to. The experience was pathologised in terms of the concern surrounding the level of paranoid feelings attached to delusional thinking, particularly the effect it would have on the individual’s social relationships:

> M: Hmm I think I don’t know people like think that you give them a cup of tea someone has put something in it
> C: They think people are judging them or making opinions
> M: may lack what an ordinary person’s routine would be like if they hear voices they might not want to shower they might think the water is acid
> E: effect on other people like relationships turning against each other

The process of medicalising these irrational thoughts enabled the young people to understand why these individuals may behave anti-socially. In this framework, medicalisation helped the young people to emphasise their level of concern and empathy towards the individuals experiencing these paranoid thoughts. The experience of having delusional thoughts was utilised as an explanation to justify behaviour not considered socially appropriate. This level of defence illustrates the benefits of framing their responses within a medicalised perspective to sugar coat their answers to the AR (Burns & Schubotz, 2009), thus avoiding any sign of stereotypical or stigmatising attitudes.

Nevertheless, the process of pathologising and medicalising again did nothing to reduce the level of fear associated with these experiences. The young people clearly thought that the experience of delusional beliefs would be very disturbing:

> C: good thoughts and bad thoughts and they overpower you so you can see that they get mixed up with what you are thinking because there is so much going on…got different things going on in their head that doesn't make sense

The level of empathy over this experience was strong. However, during the PRFGS the experience of having delusional thoughts were graphically described in terms of the prospect of causing more harm and unpleasant experiences. Responses held fewer feelings of empathy towards the lived experience of the individual, with less need to sugar coat their responses to their peers (Burns & Schubotz, 2009):

> R2: I couldn't think of any positives, but for a negative I've got that they're delusional
> R1: Schizophrenia's not exactly pleasant condition having imaginary fantasies of god knows… Sort of having imagining things that aren't there, who knows what effectively.
> R2: And they think that you're hurting them and you're not.
> R5: Disturbed thinking…That it can affect you so badly that they might get to the point where you start thinking about harmful things like when it starts to become physical as well as just mental.

The effect of medicalising the experience of delusions in this dialogue between the young people made the experience more frightening and dangerous. There was a lack of ability for young people to be able to relate to the experience of having delusional thoughts. The consequence of this was an increase in social distancing from such dangerous behaviour. These responses involved a genuine feeling of anxiety and fear attached to fantasies and an imaginary world that is disturbing.

It is important to increase our awareness of how these young people understand the experience of delusional beliefs in a more realistic approach than trying to sugar coat our discussions. The anti-stigma approach often taken in literacy interventions has prevented young people from expressing justified anxieties and worries associated with such behaviour. Avoidance of entering such a dialogue could make young people unequipped to understand the nature of psychosis and increase the level of fear associated with this taboo topic with professionals (Bertolote & McGorry, 2005; Potts, Gillies & Wood, 2001).

5.2.3.3 Concluding observations

The comparison of these research results illustrates important points when understanding lay understandings of psychosis among young people. Young people shape their dialogue according to their audience, as amongst adult professionals medicalisation dominated dialogue and amongst their peers the young people had the ability to appreciate and relate to the lived experience of psychosis. The four dimensions of Haslam's (2007) folk psychiatry model do not cater for young people's ability to explore the lived experience of psychosis and understand the experience from a wellbeing, rather than illness, perspective. It is therefore important to be aware of how young people may not necessarily pathologise or medicalise the experience of psychosis, which is often assumed.

Secondly, derogatory language used by young people is not always intentionally derogative in context. The lack of diagnostic or clinical terminology used during the PRFGS allowed young people to express their concerns about the level of potential aggression or violence involved in psychotic experiences. This illustrated genuine concern for the safety of individuals and increased the level of empathy in their ability to understand the lived experience of psychosis.

In contrast, when young people used medicalising terminology distancing increased, and there was a notable avoidance to engage in dialogue about violence or aggression involved when experiencing psychosis. This shows how attempts to follow an anti-stigma agenda and the use of formalised medical jargon can lead to not addressing young people's literacy needs appropriately. It is important instead to explore and value the openness and colloquial dialogue generated when discussing psychosis to address young people's psychosis literacy needs.

5.2.4 RQ2: What sources of knowledge do young people draw upon in order to construct their understanding of psychosis?

To understand the levels of the stigma involved in young people's dialogue about psychosis, it is important to appreciate where their information and knowledge about psychosis originated. This is demonstrated in Figure 8 below, where a thematic analysis revealed interpretations of young people's stigma during the ARFGS and PRFGS:

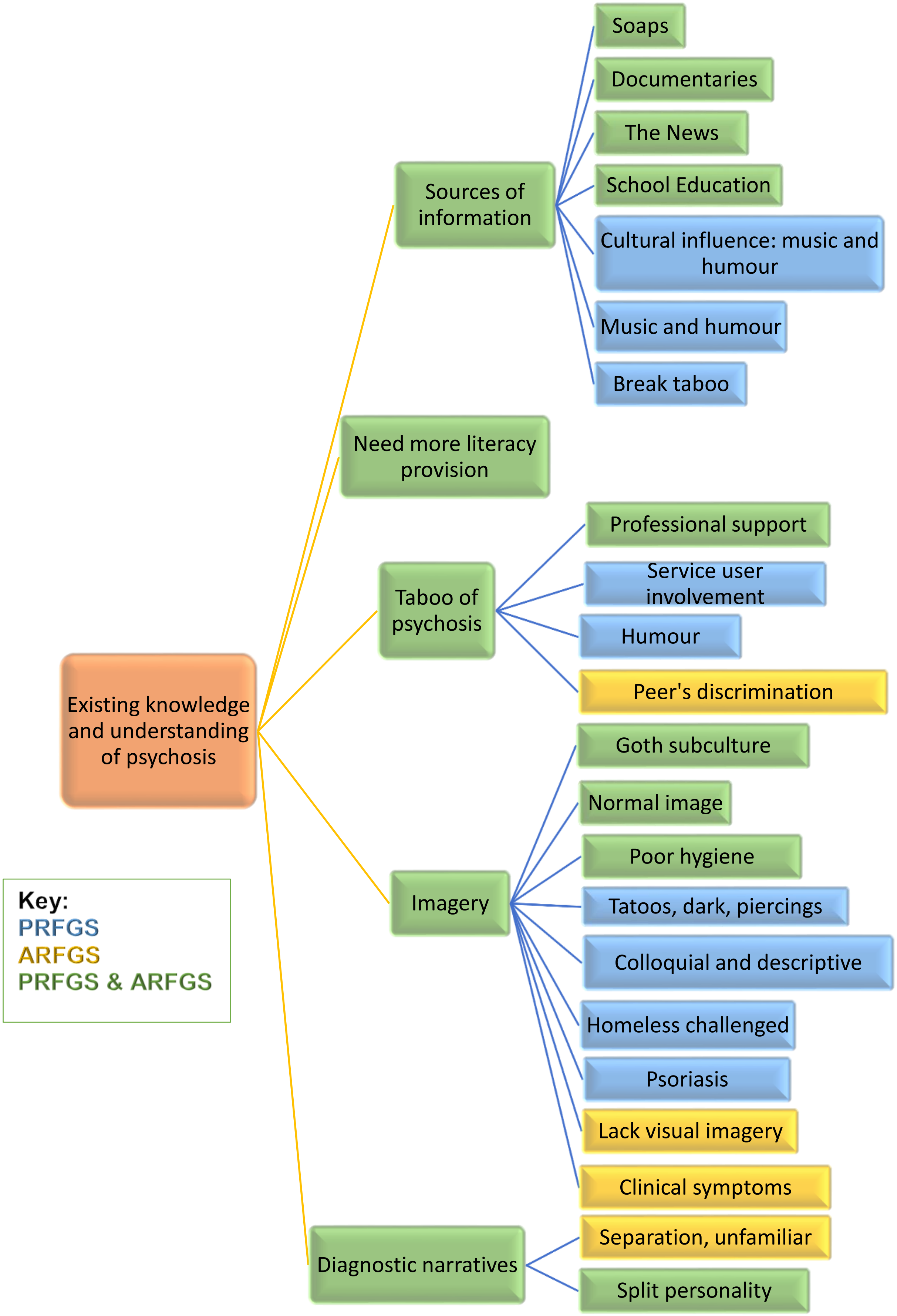


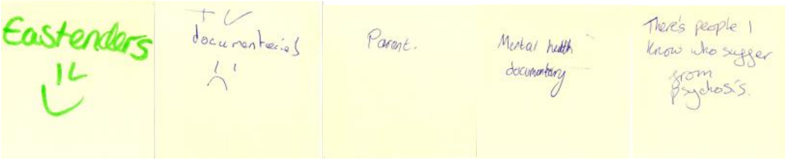
Figure 8: Existing knowledge and understanding of psychosis

A post-it note ranking activity enabled an exploration of these different themes during the ARFGS. The results are displayed below in Photo 1.

Photo 1: Ranking post-it notes

From this activity, it was clear that the young people placed a great deal of emphasis on the role of media as the most influential source of information. During one of the PR-led focus group sessions, post-it notes also explored where the peer participants had obtained their information about psychosis (without the ranking process):

Photo 2: Post-it notes in peer research focus group session



Results similarly showed the importance of the influence of the media when interpreting how young people expressed their understanding of psychosis. This influence has significant relevance towards feelings of stigmatising imagery of psychosis.

5.2.4.1 The influence of the media – soap characters

There was significant concern expressed during the ARFGS about the influence of the media for generating stigma. This concern focused on how such imagery would make young people stereotypical and create inaccurate knowledge about psychosis:

> R: I don't think it's very accurate because the media just shows stereotypical views and behaviours associated with them but I don't every case is the same
> C: kind of dramatic, it wasn't realistic, it was only the voices side of what has been said not the struggle or anything like that
> H: and how it's portrayed in TV programmes and stuff you wouldn't want them to babysit

This level of concern illustrates how young people were aware of the dramatic and unrealistic picture generated by the media. This level of awareness supports the fact that these young people were not naïve in accepting this media imagery. One may therefore question the extent to which research evidence portrays a worrying picture of young people being significantly influenced by the media (Rose et al, 2007; Philo, 1996; Wahl, 2002; Wahl, 2003; Wahl et al., 2003; Addington, Berzins & Yeo, 2012; Wilson et al., 2000; King, 2004; Economou et al., 2014; 2012; Schulze & Angermayer, 2005; Angermayer & Malshmayer, 1995; Angermayer & Schulze, 2001).

However, the young people's comments supported the belief that the media is a very influential source of information, and would influence 'other' young people. The young people were keen to distance themselves from the naivety of their peers, becoming the apprehensive participant as they were concerned with how an adult professional may interpret their views (Barabasz & Barabasz, 1992). The young people entered a dialogue that conformed to adult anxieties of the need to reduce the negative influence of the media on the young person's brain, as illustrated in L's comments on the stereotyping influence soap characters may have:

> L: might assume that all cases of schizophrenia are like this because that is what they have seen whereas I don't think people understand it like it might not be like this big important thing that people have to spend months in hospital for it might just be something they overcome at home

The concern expressed by L was that the influence of soaps would create the impression that all cases of schizophrenia would be the same. This concern fits into Link & Phelan's (2001) stigma model that felt that characteristics of psychosis would be stereotyped once the label is created, and thus the ability to comprehend or distinguish differences would be reduced. These anxieties mirror the AR's concerns and worries, as there was less doubt or concern about the influence of the media during the PRFGS. Instead, there was a notable amount of discussion that illustrated how the use of soap characters enabled them to understand the social effect of the illness:

> R4: Just that he was a really nice boy and then it turned it turned him into something horrible and he was horrible to his dad. He had to leave school and because they couldn't cope with it and he knew that there was something wrong with him and then when he was on his medication he was alright again.
> Q1: can you remember Jean off EastEnders, do you think that would be like a good way?
> R3: Yeah.
> Q1: Do you think that would be effective?
> R3: Yeah.

These comments show that as adult professionals we are too cautious and worried about the influence of the media, to the extent that we underappreciate the value and importance attached to the media as a source of literacy for young people. The young people have illustrated that soap characters have not led to a necessarily stereotypical image. This supports the potential use of media within MHL interventions for young people (Pinfold e al., 2003; Naylor et al., 2009; Chan et al., 2009; Saporito et al., 2011).

There were only two comments made during the PRFGS that held negative views about the media. The context of these comments related to defending the imagery of someone they knew who had psychosis:

> R2: I think the media just puts a bad light on the illness
> R1: the media may have just blown it out of proportion.

This again supports the earlier comment crediting young people's awareness of the potential problem that media can generate in terms of developing stigma and stereotypes associated with the imagery of psychosis. The ability of young people to judge messages received from the media should not be underestimated (Tones, Tilford & Robinson, 1990). There is a danger that media imagery may be deemed inappropriate and avoided, but in fact it could be utilised appropriately to add further meaning and value for the young person. Consultation with young people in the development of resources is vital if we want to ensure that the literacy supplied is meaningful and important for them (Woolfston et al., 2008; Lindley, 2009; Hartley, 2007).

Responses during the ARFGS also confirmed the value of utilising soap opera characters to help understand the lived experiences of these individuals:

> L: story in Hollyoaks, about a year ago, one of the teenage guys got schizophrenia. He like got his whole life change completely
> L: I watch Waterloo Road cos I'm sad [laugh] there was a boy who had schizophrenia in it…I haven't thought of it before, and he heard the voices, and it made him do sort of really dramatic things, I didn't ever before think, it could make someone start a fight possible, so in the short, it did make me think maybe you can have more complexities in it
> Sh: Yeah it's like Emmerdale I know it's on TV but it is a drama isn't it if somebody like suffers from psychosis people are going to be interested, like I can remember the first lesson we had everyone was like oh remember when Eastenders had got it that's how I know about it then you know I think that makes it interesting like

There is a reason to criticise the role of adult professionals in neglecting the importance attached to understanding the lived experience of psychosis for the young people. For example, in Gattuso, Fullagar & Young's (2005) project mental health professionals undermined the everyday construction of depression. Adults fear such discussions and are also dismissive of the relevance and importance attached to engagement in such dialogue.

The value of using soap opera characters as a source of literacy requires re-evaluation. In fact, the results of this research show that young people related to the lived experience of soap characters. There was no intention of stereotyping, but it created a genuine general feeling of sympathy and understanding.

5.2.4.2 Documentaries

During the PRFGS the use of documentaries was valuable because it illustrated the real and explicit experiences of psychosis. The focus of this experience created an imagery based on a significant amount of violence and aggression:

> R1: No that would be effective especially the documentary of the little girl who was screaming, scratching her arms causing herself to bleed to understand how much of a serious subject it is…
> R2: there was a documentary of a six or seven years old who had schizophrenia. Like everyone was so very sympathetic to her and a bit patronising and she needs to be separated from her family like every weekend before she likes attacking her brother or something so she got treated very well.
> Q: Did you get the information from anywhere else? R1: No, specifically from that documentary but it was rather accurate; it had several psychiatrists on…
> R2: I think that getting the information from a documentary is reliable because its why they put it on TV and shown as a documentary it needs to be like true and objective

One could argue that this type of dialogue encourages stigma, based on Link & Phelan's (2001) labelling process by associating psychosis with unfavourable characteristics. Accordingly, the result could encourage the process of devaluing and excluding these individuals socially.

However, there is no evidence that this was the young people's intention. It is important not to misinterpret young people's responses but contextualise their dialogue. This illustrated the emphasis on documentaries being accurate in terms of illustrating the level of severity of this illness and not to hide the truth. The authority of psychiatrists also sanctioned the truth of documentaries.

The message from this dialogue does not represent the image of young people who are stigmatising, stereotypical, or naïve, but instead shows the importance of understanding how severe such experience can be. The young people suggested that an anti-stigma agenda has hidden the truth. This can inform the development of future literacy strategies in terms of appreciating what young people will understand and interpret as the truth. Dialogue approaches can instead potentially open sensitive and often explicit discussions on psychosis (Lindley, 2012).

The appropriateness of literacy interventions that have utilised media to reduce stigma requires questioning. For example, Chan et al. (2009) utilised a video clip entitled 'The Same or Not the Same', which purposefully avoided any explicit or violent imagery. This avoidance may question the level of trust that such literacy interventions have for young people. However, no opinions from the young people about the use of the documentaries utilised in Chan et al. (2009), Pinfold et al. (2003), Naylor et al. (2009) or Saparito et al. (2011) can evaluate whether this was an influential factor or not. This is a flaw in terms of not appreciating how young people may interpret documentaries. Documentaries are carefully portrayed and sanctioned as appropriate by adult professionals without enough involvement from young people to evaluate whether they suitably meet their literacy needs.

For example, one point made by R4 was the suggestion to widen the picture of understanding the lived experience of psychosis using documentaries. This is an area that R4 felt should be addressed to prevent just seeing one person's life story using documentaries:

> R4: I think seeing people suffer from psychosis you kind of learn about some parts of it so its reliable in one sense but not everyone suffers the same things and has the same sort of conditions and things so its reliable in some sense but obviously you're not seeing the full story all the time, you're just seeing one person going through it not the whole disorder.

This acknowledgement again shows the level of awareness of young people wanting to avoid being stereotypical in their understanding of psychosis. On reflection, this again does not correspond to earlier media literacy interventions framed within a narrow anti-stigma framework to make the individual someone they could relate to (Chan et al., 2009; Pinfold et al, 2003; Naylor et al., 2009; Saparito et al., 2011). These interventions do not necessarily cater to the benefits described by R4.

Meanwhile the value of using documentaries during the ARFGS appeared to conform to the previous anti-stigma agenda, as C in D college noted how documentaries may illustrate how psychosis could affect anyone:

> C: I do like sitting down to watch documentaries because it's just amazing on how you look at someone and how their life changes because it's just part of life I guess like anyone could have it anyone could be normal and then one point life could just change so you just don't know when it's going to happen I guess

M in S college, on the other hand, did not feel that the use of documentaries was entirely truthful, and commented on how they could focus on the stereotypes related to violence and aggression:

> M: When they didn't take their medicine they thought that that they were going to kill them all the stereotypes really and the dangers

The anti-stigma agenda response seems to correspond to the level of caution called for from the AR's perspective. Hence, a level of caution is warranted when understanding young people's responses, as this dialogue may be shaped to avoid appearing stigmatising to please the AR.

5.2.4.3 The News

In both the adult and PRFGS there was scepticism about the role of news in creating the association of psychosis with dangerous behaviour. The imagery was created in the context of viewing schizophrenics as murderers:

> L: On the news as well when you hear about someone who's killed someone they normally say they are schizophrenic or like I can't think of an example, isn't it Raoul Moat isn't he schizophrenic he probably was but I'm just saying it's like that's just an example of using it
> R3: And stuff like that, and hear that in the news, and it's pretty like negative like on people with the illness who aren't dangerous at all.

These comments show the ability of young people to see through the influence of the tabloid press. The sensationalism associated with the terms psychotic and schizophrenic fits Link & Phelan's (2001) stigma model to discredit and disassociate these individuals from society.

The moralising dimension suggested by Haslam (2007) could potentially influence the young person's perspective through the impact of imagery created by the news. The news primarily directed blame at behaviour and actions through an explanation of their mental health. The principal point to note is even though the news was influential, the young people were able to question the level of negative association with psychosis and did not accept such views.

5.2.4.4 School Education

During the ARFGS, there was criticism of the nature of discourse that existed about psychosis within previous educational experiences at secondary school:

> H: I did it at GCSE History which was a massacre with schizophrenia and said that the voices in his head would tell him to kill people at school because they hated him and were horrible to him and stuff like that
> M: The way the teachers talk about it stereotype didn't say any other point like they didn't say any positive
> H: I think yes because there is a dark cloud over the subject so in schools they tell you like schizophrenia and stuff but they don't really explain it they just make out that it's seeing things and being angry and stuff

These comments illustrate the amount of stigma that existed from the young person's perspective within their school environment. The young people had awareness of the problems that existed when discussing psychosis and used this as a form of justification why schools needed to take a more active role to reduce such stigma. This justification fits with the concerns raised by Potts, Gillies & Wood (2001) that young people need to know how to approach and talk about the topic to improve help-seeking behaviour.

The reason young people have been disappointed with the approach taken by schools could be due to the lack of priority given to mental health approaches in schools. The TaMHS project, for example, was criticised as obstructing academic work in secondary schools, and was only supported for a 3-year period (Formby & Wolstenholme, 2012).

However, when MHL approaches have addressed the topic of psychosis an anti-stigma agenda has dominated (Economou et al., 2011; Chan et al., 2009; Schulze et al., 2003; Conrad et al., 2009). One could argue that the young people's responses have conformed with this agenda in agreeing with the AR's aim to improve psychosis literacy to reduce the level of stigma attached to this illness (Nichols & Maner, 2008; Barabasz & Barabasz, 1992).

Responses during the PRFGS were not orientated within an anti-stigma framework. There was no elaboration or criticism against their school's lack of MHL provision:

> R2: only briefly touched on it but I think if it was taught in secondary schools and stuff like that then it would be better
> R5: Haven't really, maybe been brushed over in a PSHE day or something but not really

The lack of exploration could show a disadvantage of using PRs in that it may have prevented the right level of probing needed to explore their opinions (Jones, 2004). Or alternatively, one could interpret the lack of criticism as an illustration that the peer participants were less concerned about their fellow peer's level of stigma and not influenced by the AR's concerns and anxieties.

These responses overall, however, do support the fact that young people felt that there was a need for schools to inform their knowledge and understanding about psychosis. This supports the level of interest and support expressed by young people to increase the provision of psychosis literacy within schools (Williams & Pow, 2007; Woolfston et al., 2008).

5.2.4.5 Cultural influences

One theme generated during the PRFGS was two comments that related to the term 'culture', when asked where they had learnt about psychosis. Culture for the young people meant references to everyday life and did not enter a clinical or diagnostic framework:

> R5: Because there's references in like everyday life to mental health disorders and stuff and people and there's different ways when people like try and be serious about it they do try and be sympathetic and stuff but if you look at comedy and stuff you sometimes when you see people like try to take the mick which isn't really a nice thing to do but I mean it happens in all aspects of life.
> R1: Some songs like mention like references on some music even mention self-harm and stuff, it depends where.

R5 clearly understood the implication that the use of humour could be viewed as being insensitive. However, this was not meant to be the case when used in the context of comedy and general dialogue. The use of stereotypical terminology in everyday language should not necessarily be interpreted in its literal translation when considering young people's use of language (Schulze et al., 2003; King, 2004; Wahl, 1992; Taylor & Gunn, 1999). Hence, R5 indicates how the use of humour can happen in all aspects of life, and that reference to psychosis in a humorous context should not be taken too seriously with intention to encourage the process described in Link & Phelan's (2001) stigma model. The social meaning of psychosis requires further exploration to prevent misinterpretation of young people’s use of language (Wills, 2005; Wills et al., 2006).

The benefits of using PRs was that it opened the use of shared common language, as the young people were able to express shared meanings and experiences about the terminology used to describe psychosis (Kirby, 1999). This form of local knowledge between community members gives research the opportunity to explore the social meaning of psychosis (Manderson & Aaby, 1992). R1, for example, explored references to psychosis within music lyrics, a context of talking about psychosis which may help break the taboo surrounding the topic. Again, this context is without intention to be malicious or encourage stigma. An understanding of how terminology is used and understood by young people goes against previous research measures of stigma when focusing on specific terms used to describe psychosis (Bailey, 1999; Rise et al., 2007; Nisha et al., 2005; Wright et al., 2011; Jorm & Griffiths, 2008; Angermayer & Dietrich, 2006).

During the ARFGS there were no comments about the cultural context of psychosis terminology. PRs did explore an area that was perhaps neglected as irrelevant but important for the young person when making sense of the experiences of psychosis (Cleaver, 2001; Moore, Saunders & McArther, 2011; Smith et al, 2002).

5.2.4.6 The taboo of psychosis

Overall, the research results have shown that the young people felt that most of their knowledge about psychosis originated from the media or from general everyday discourse. The young people felt that it was a taboo topic to approach within the school environment. This level of taboo adds to the stigma that exists surrounding psychosis, a condition socially excluded and devalued, which fits into Link & Phelan’s (2001) stigma model’s process of encouraging separation, status loss and discrimination.

We shall now consider the extent to which a taboo existed when or if young people discussed the topic of psychosis with their family. During the PRFGS, the young people expressed great difficulty in engaging in a conversation about psychosis with their family, as they found that it was a sensitive and taboo subject:

> R3: I think it depends on the parents it may be a sensitive topic so they might be a bit iffy on it.
> R1: its a taboo subject people don't talk about it, people don't want to talk about it, people don't want to know about it or know anyone with it.
> R4: I just think some people might not talk about it within certain social situations.

The reason for this level of taboo was based on a set of social values that decided what is socially acceptable to discuss or not. These social values derive from an adult world which directs what is appropriate for a young person without considering what was important and meaningful for the young person (Tones, Tilford & Robinson, 1990; Lindley, 2009; Dex & Hollingworth, 2012). This has important implications on what barriers exist to young people accessing relevant mental health services due to the level of importance young people have attached to the support they receive from their family and friends (Sheffield, Fiorenza & Sofronoff, 2004).

The difficulty of breaking the taboo associated with psychosis within families also occurred during the ARFGS. L described the prospect of engaging in dialogue about psychosis as being uncomfortable and C recognised that it was not an easy topic to bring up in general conversation:

> L: I think I would be quite uncomfortable if I'm quite honest
> C: Just kind of a hard subject to come up with isn't it [laughing]. You don't really want to say oh I'm doing about psychosis schizophrenia by the way just to let you know [laughing]
> C: It's just not something that comes up in everyday conversation is it
> L: Yeah I think it would be uncomfortable and awkward to talk to somebody because if they have a personal experience of it you don't really want to discuss

The influence of certain social conditions determined whether the young people felt comfortable to enter into a dialogue about psychosis. This confirms how young people may become more cautious and sensitive when approaching this topic, and the reason schools have avoided discussions of mental illness, preferring instead to focus on topics related to mental wellbeing (Kidger et al., 2009; Armstrong, Hill & Secker, 2000). C supports this feeling as she felt a discussion about psychosis was not perceived to be relevant or important for the young person's life in comparison with topics such as sex and drugs, which have been prioritised in the PSHE curriculum (Kidger et al., 2009).

The influence of talking to someone from a professional background made the young people feel that they were able to enter into a dialogue about psychosis. This was because the young people felt that these individuals would be more aware and knowledgeable about mental health:

> Q1: where do you get like information about psychosis?
> R3: Dave probably.
> Q1: How come off him?
> R3: Because he works in mental health
> R4: It might be due to their jobs seeing as they're both paramedics
> R2: Yeah no I think my mum would probably I think she'd like me to know about it and I think she'd want to tell me about it because she's a children's nurse

This proves the value placed by young people on engaging in discourse about psychosis from individuals that have a professional background. It enabled young people to have a purpose to discuss the topic of psychosis. Young people felt comfortable to break the taboo nature of this topic when in an environment directed by professionals (Williams & Pow, 2007; Armstrong, Hill & Secker, 2000; Woolfston et al., 2008).

The level of professionalism reflected by the adults encouraged more trust and openness to engage in dialogue about mental health, which would have been otherwise trivialised or devalued (Naylor et al., 2009; Armstrong, Hill & Secker, 2000). This feeling occurred during the ARFGS, where there was concern that other adults, not from a professional background, would be more likely to express stereotypical connotations of the image of psychosis and would be uninterested in engaging in a dialogue about psychosis:

> Sh: I think I will mention it like that we are doing this research task later on when it's more hands-on but not at the moment I don't think my parents would be really interested in it
> M: Like if your friends if your parents are educated as Drs or nurses then it will be easier to talk about it than a normal parent, the normal parent would perceive them as stereotypes of it like see them as something strange and how it actually is then it would be easier to talk to but if your parents think that you are just going to start hearing voices then like they might just say no you don't have it because they don't have it
> L: My auntie works in mental health she's a nurse there so she talks about it in a more realistic way you know she knows more about it than I don't think we got taught it at school I don't think they really understood it they were just reading it off where ever they found it from the sort of sees kind a

> lot so she just she will say about certain trait's or something she tells me about that.

M expressed concern that if you had normal parents, without a professional background, there would be more chance of engaging in preconceived stigmatising ideas about psychosis. This feeling is comparable with young people's views that general teachers have inadequate training to carry out sex education in their schools (Ellis, Pagarani & Fauth, 2009). In these cases it has been found that young people preferred the opportunity to engage in dialogue about sex with peer educators, as they felt less looked down upon and had more opportunity to clarify thoughts and ask questions (Lupton & Tulloch, 1996). Although this was not related to adults being stigmatising, it illustrates the importance attached by young people in feeling that they can talk openly with shared interests that relate to their needs (Forrest, Strange & Oakley, 2002).

Similarly, during the PRFGS, young people felt able to engage in discussion about psychosis with someone they knew had experienced a psychotic experience. The young people felt that this factor made it easier to break the taboo of discussing the topic. There was less focus on the benefits professionals brought in the role of breaking the taboo nature of this dialogue:

> R4: Just my auntie's bipolar and then I have other people that I know like suffer from other forms of psychosis and I think sort of different to how everyone else like thinks of them being portrayed like on TV where they're seen as being just mental and things, obviously in like a real-life scenario its quite a lot of difference.
> R4: Yeah because obviously I'm related to someone, we talk about it sometimes but I don't know whether its easier to talk about that with them, I suppose it is because like they've sort of seen it and things but I don't think we take it that serious, like we don't every time we discuss it we don't often sit and have like a cup of tea conversation about how serious it is and how its a proper issue, sometimes we can just talk about it like everyday sort of context rather than having to just make it really meaningful but I don't think it happens like that kind of joking about with it or anything just sort of think its normal so we just talk about it normally.

These conversations were valuable for R4, as it enabled her to understand the real-life experience of psychosis. This real-life imagery was effective to combat the stigma often portrayed incorrectly through the media. The experience of having direct contact with someone with psychosis reduced the taboo of discussing psychosis and instead allowed it to be easier to enter a normal everyday conversation. These responses support research evidence that has utilised the method of direct contact with service users as a method of MHL (Pinto-Foltz et al., 2011; Conrad et al., 2009; Schulze et al., 2003; Pinfold et al., 2009; Chisholm et al., 2012). The explanation given from this evidence is that it enabled the young people to relate to these lived experiences. However, R4 explained the benefits in terms of reducing the level of seriousness associated with the psychotic experience, showing the benefits of avoiding a diagnostic clinical discussion which would only increase the process of labelling, separation, and status loss, all stages in Link & Phelan's (2001) stigma model. For example, the use of humour in R3's family helped the process of reducing the level of taboo attached to the topic:

> R3: My dad's side of the family would probably just have a laugh about it, they wouldn't, they're quite open, they'd just talk about it whereas my mum's side of the family would probably be like quite hush hush about it

This clearly links with R3's statement and the previous comments made about the influence that culture can create in terms of establishing a humorous dialogue to talk about psychosis. This context is not negative or stereotypical in context, but valued as a useful tool to break the taboo nature of the topic. Thus, the value of using peer research methodology is that it has opened the context and meaning attached to young people's discussions that could have easily been misinterpreted within a stereotypical framework.

In contrast, during the ARFGS participants felt more comfortable to discuss psychosis with their friends:

> A: How about friends, do you find you could talk about it a lot easier with friends?
> L: Yeah
> C: Yeah. More comfortable with friends it's easier

This illustrates that the level of taboo will change according to the social circumstances young people are in, which supports the rationale for utilising PRs to engage young people into an open discussion about their psychosis literacy needs (Kirby, 1999; Bland & Atweh, 2007; Grundy, 1996). It is important that the social interaction that young people engage in between adults and their peers is appreciated in terms of how it will influence the taboo nature of the topic (Monahan & Fisher, 2010).

Alternatively, young people expressed the dangers that may arise from peer influence. This perspective focused on the prospect of an increase in discrimination:

> L: Friends can just go friends can just if they hear about it they can just leave whereas with your family they have to stay with you and put up with you I mean they are more inclined to stay with you whereas with friends if they hear about it they, especially now this age friends just come and go don't they.
> H: I think it's a tricky topic to bring up some people might think that you are talking about it for a reason that they assume that you have got problems or something
> R: I think it would be easy to discuss if you didn't have it but obviously if you have it it would be harder to discuss, you would be scared that others would judge you

The focus on the dangers associated with the influence of peer relationships seems to fit an adult-focused deficit framework perceiving young people as vulnerable and requiring protection against the influence of their peer's level of stigma (Morgan & Ziglio, 2007; Ecclestone & Hayes, 2009a; 2009b; Ecclestone, 2007). Alternatively, the influence of having an AR present may have enabled the young people to express these concerns more freely due to the type of dynamics involved in their relationship with their peers, and the level of power differences that have existed between the PRs and their participants (Kirby, Laws & Pettitt, 2004; Kirby, 1999).

Whereas, during the PRFGS the opportunity to admit to this concern was limited because they were actively discussing the topic among their peers. Nevertheless, R2 did support the responses from the young people during the ARFGS in terms of the difficulties that exist in breaking the taboo nature of this topic with their friends:

> R2: not able to talk to my friends about it because it would be a bit awkward and probably wouldn't be interested

Overall the young people's responses have supported the opportunity for young people to engage in discussions within their social circles, particularly family and friends, to reduce the level of taboo that exists. The benefits of humour, personal contact, personal experience, and peer support are the main themes in reducing the level of taboo involved. These factors require careful appreciation in their full complexity when considering how to implement an effective form of psychosis literacy.

5.2.4.7 The physical imagery of psychosis

When young people described the physical imagery of someone with psychosis, they were engaged in a process of separating themselves from the individuals experiencing psychosis. The experience was not relatable but socially disapproved or separate, conforming to the mental health stigma model proposed by Link & Phelan (2001).

For example, during the PRFGS, the PRs asked the young people to draw pictures of individuals with psychosis. The outcome of this activity was the association of dark colours, tattoos, and piercings, which overall made these individuals stand out socially.

> Q1: You've drawn it in pink, is there any reason you picked pink, its just everyone else has drawn it in sort of dark colours but you've drawn it in pink. R5: Its just I like the colour pink but no not really like because I should have drawn it in a different colour really because usually you associate it with men just because like what it shows on the TV and stuff but.
> Q1: So do you all associate it with dark colours and grim things?
> All: Yeah.
> R4: Because its not very nice.
> R4: Tattoos, lots of piercings.

The influence of the media was notable in their drawings, as they linked to the imagery of masculinity and social class, which is consistent with previous research evidence that has been critical towards media's portrayal of psychosis (Wahl, 2003; Wahl et al., 2003; Wilson et al., 2000; Schulze et al., 2003; King, 2004; Taylor & Gunn, 1999). In fact, 63.6% of young people received information about psychosis from the media, of which 51.7% was from TV imagery (Schulze & Angermayer, 2005). The media has also been seen to legitimise and reinforce such negative imagery (Secker et al., 1999).

The negative nature of this imagery has dominated the interpretation of young people conforming to a stereotypical and stigmatising image. It has neglected any consideration of young people's level of literacy in terms of the social meaning attached to the imagery of psychosis. Parallels of such misinterpretations in studies by Wills (2005) and Wels et al. (2006) occurred in terms of how young people understand the social meaning of being obese. This can be demonstrated in R4's awareness of the link between being homeless and the experience of schizophrenia:

> R4 What I'm saying is that there's just like a stereotypical like look like him he's a homeless man…homeless people always seem to have like mental disorders don't they like they're always seen to be like schizophrenic or something like that…And they always seem like you always see lots of like homeless people talking to themselves, I don't know whether that's to do with anything but…

R4 acknowledges that such imagery was stereotypical and shows good awareness of how society may interpret the meaning of talking to yourself, questioning whether such interpretations are correct when presented with an image of someone who was homeless:

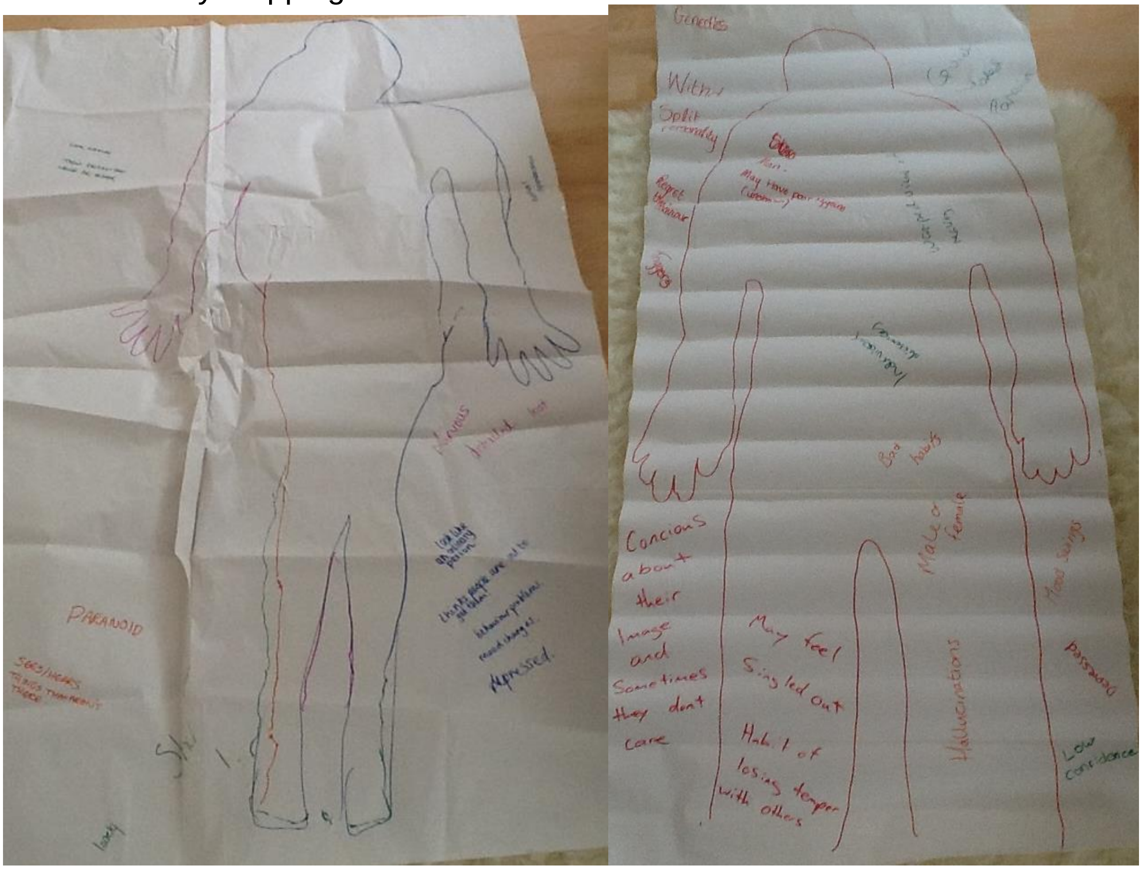
Image 3: Homeless man

The level of responsibility society has in creating such interpretations is a key factor that young people felt required exploration. Reaffirming the importance of applying the power threat meaning (PTM) framework when addressing young people's psychosis literacy needs within a social and relational context (Johnstone et al., 2018).

It is also important to be aware that dialogue commenting on how someone may look different physically occurred during specific activities in which the PRs asked the participants to describe how a person with psychosis would look. There was an expectation that young people would enter the process of showing and labelling these individuals as different, even though they may not really think they do. However, one could view such influence of PRs as an indicator of the lack of experience and authority held by PRs in conducting focus group sessions, leading participants into responses that shape their own preconceived ideas about psychosis (Jones, 2004; Kellett, 2010).

This may explain why there is less descriptive physical imagery discussed during the ARFGS. There was no direct activity which asked the young people to consider the physical characteristics of an individual with psychosis involved, except an opportunity during the body mapping activity which only resulted in young people putting words that they associated with psychosis in the outline (see Photo 3):

Photo 3: Body Mapping



Whereas the PR’s resources included an activity that asked the young people to comment about images of individuals displaying different social and emotional characteristics. The importance attached to such imagery illustrates the PR’s insight to utilise suitable engaging methods to identify/prioritise issues not considered before (Smith et al., 2002).

There was, however, a link made during the ARFGS which related psychosis to the imagery of gothic subculture:

> C: The person in Hollyoaks like was made to be like gothic person so like you give the image that only people like you know gothic people like experience it

C confirms the influence that the media had in generating a stereotypical image of being a Goth and having psychosis. C expressed this view in direct response to the AR's questions about the influence of the media, illustrating the importance for C to appear to be politically correct and avoid being seen as stereotypical.

The link made to Goth subculture requires further consideration, as reflected in similar findings made by Scott & Chur-Hansen (2008) where the concept of being an emo was described by the young people in relation to how individuals expressed their emotions through overt displays of self-harming and the type of music they listened to. This seemed to influence how young people were able to explain the experiences of psychosis. For example, in Scott & Chur-Hansen's (2008) study emo subculture was utilised in the context of explaining how the expression of feeling down can be normalised within a subculture. The result of this association could have the effect of making an individual physically different as a requirement of acceptance by the subculture that the young person is a part of, in this case as a Goth.

This influenced the choice of one PR to present an image of an individual dressed as a Goth, to develop a discussion of the portrayal of someone with psychosis:

Image 4: Goth man

This proves how youth subculture can challenge the earlier negative connotations that have been associated with separating them from us through the process of physically describing someone different (Link & Phelan, 2001).

During both the PRFGS and ARFGS the lived experience of poor hygiene was an indicator that could make someone physically different if they had psychosis. The dialogue during the ARFGS was in the context of discussing the clinical symptoms of psychosis:

> C: also their appearance as well. I mean some people don't want to get up and get washed they just don't look after themselves and they are pale and you can see a dramatic change from someone who's been like that they do their hair and their makeup and dress nicely to someone going straight to ruff [laugh] basically and that's how you can really tell
> M: may lack what an ordinary person's routine would be like if they hear voices they might not want to shower they might think the water is acid

There was no sign within this dialogue that there was an attempt to devalue or exclude these individuals when engaging in a discussion of how the individual may look dishevelled. There was more concern towards how the psychosis affected their lives, and the focus on a biomedical explanation helped to reduce the blame for the lack of hygiene that the young people discussed (Haslam & Kvaale, 2015; Haslam, 2007). These individuals were conscientious about how they looked, but because of the psychotic experience, they had no energy or could not be bothered to take care of themselves:

> C: Like she was conscientious about her image, but they can't be bothered to do anything, you know what I mean like
> B: Yeah
> C: But they have no energy some days
> Sh: But some days they do, so like so they can be conscientious sometimes and that's ok

The medicalising context of this dialogue regarding hygiene increased the level of sympathy attached to the individual's change of appearance. The benefits of understanding the social meaning attributed to psychotic experience produced non-judgemental reasons why someone may be neglecting their personal hygiene needs.

However, the young people were also aware of the potential dangers associated with increased social distancing due to the exhibition of such undesired and unpleasant characteristics (Haslam & Kvaale, 2015). B, for example, recognised that there is a danger of stereotyping when discussing the way in which individuals had poor hygiene:

> B: stereotyping to be honest, they would have poor hygiene and unshaven and stuff like that

This demonstrates awareness of how society may attempt to disassociate itself from these individuals with socially-disapproved physical characteristics, as suggested by Link & Phelan's (2001) mental health stigma model.

Whereas, in the PRFGS, there was less attempt to show awareness of the impact stigma may generate from their discourse surrounding the possible difference of physical imagery associated with lack of hygiene:

> R1: You don't imagine it would be the same as what you would look like, you imagine them to be a bit sort of dishevelled and grubby and just not very good on personal hygiene and stuff
> R2: they can't look after themselves properly…
> R1: Don't care about their appearance any more.
> R2: They have like greasy hair.
> R3: They don't do their make up…
> R4: you can't force them to have a bath, and you can't force them to get changed and stuff
> R1: They have hollow cheeks because they can't, don't want to eat sometimes.

There were also no attempts made in this discourse to link the reasons for a lack of hygiene with the clinical symptoms of psychosis. The result of such dialogue was that the discourse was noticeably more colloquial and descriptive in nature. One could argue that the different nature of this dialogue shows the benefits of using PRs, as there was no sugar coating in their responses (Burns & Schubotz, 2009). The young people did not have to feel that they had to correspond to an anti-stigma agenda within their discourse. The young people were more relaxed to enter more privately, than publicly, acceptable dialogue focused on being politically correct (Barabasz & Barabasz, 1992).

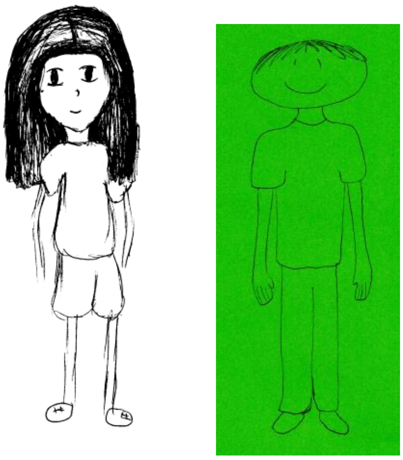
The terminology used to describe the physical difference associated with a lack of personal hygiene was graphic and quite scary. This is particularly the case within the use of visual methods, which often resulted in more graphic terminology. The use of more graphic language does not necessarily mean that we interpret young people as intentionally stigmatising. It displays their genuine concerns and worries associated with the experience of a psychotic episode (Smith et al., 2002).

In fact, there were also several responses made during both the PRFGS and ARFGS which felt that it was inappropriate to provide a typical image of someone with psychosis. This level of resistance does not fit in the model proposed by Link & Phelan (2001), as the young people described someone with psychosis as normal and unable to distinguish any different physical characteristics. There was also an acknowledgement that such a process would be inappropriate and stereotypical, and would incorrectly show that psychosis could only affect a certain group of society:

> R3: A normal person…because you can't really tell if someone's got schizophrenia
> R2: you can't tell from just by looking at someone whether or not they have a mental disorder so they could just look like a normal person
> R1: It's below the skin.
> R1: You can't really tell by looking at somebody so.

Hence, when the young people drew someone with psychosis, they drew normal women and men without any physical characteristics to show them as having psychosis:

Drawing 4: Normal physical characteristics



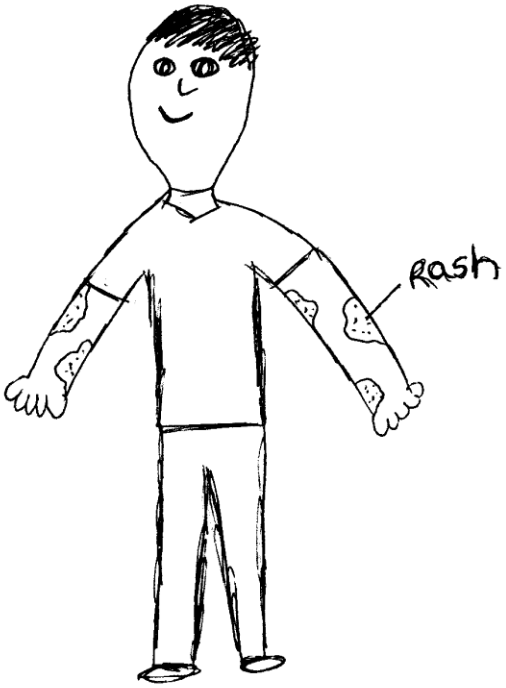
Similarly, young people during the ARFGS challenged the stereotypical imagery of how someone with psychosis could look. The young people acknowledged that it was stereotypical to physically identify psychosis:

> C: I think it's very stereotypical so I don't think they have a certain look because it's all mental not physical
> C: anyone could get it and didn't have to be a sort of different type of person like to have a psychosis

During the peer-led focus group, there was also uncertainty and confusion when asked what someone with psychosis may look like. This made R2 confuse the term psychosis with psoriasis, and they therefore drew a picture of someone with a rash and stated that scratching would identify the individual:

> Q2: Do you think it would be like visible that they had it or?
> R3: Well it depends how severe it is I suppose but then again I've never really met anyone that I know that has schizophrenia.
> R2: Mine's a rash.
> R2: I don't know, like, I don't know what I'm thinking of,
> Q: Erm we've laid some images our, on the table and erm you just have to like identify whether you think any of them have schizophrenia or psychosis and like explain why you think that.
> R2: Could she have it because she's itching her head.
> Q: Erm, okay. It's not to do rashes.

Drawing 5: Psoriasis



The level of confusion R3 indicated in this dialogue reflects earlier research results that have been critical of young people's level of MHL in terms of how young people have confused mental illness terminology with learning disability terminology (Bailey, 1999; Rose et al., 2007; Nisha et al., 2005). Instead of criticising young people's level of literacy, one needs to appreciate the difficulty experienced by young people in understanding medically-orientated terminology, and that adult professionals often incorrectly assume that young people will know and understand such terms. The use of lived experiences, such as vignettes, can be more useful when engaging and evaluating young people's level of understanding and knowledge (Wright et al., 2006; Secker et al., 1999).

The use of diagnostic terms in mental illness has the potential to be confusing and unfamiliar to a young person. It is important however to credit young people's ability to rationally consider whether there would be a change of imagery involved, and acknowledge their lack of knowledge and understanding. This is an important starting point to enable young people to explore what knowledge and understanding they need before making the mistake of assuming and generating further stigma. For example, R3 was able to clarify with his peers the mistaken terminology of psoriasis to ensure that inappropriate or misidentified identification of psychosis does not occur in the literacy provided (Wright et al., 2006; Wright, Jorm & Mackinnon, 2012). The clarification sought may not have occurred if an AR had conducted the research, supporting the fact that young people are more likely to seek help and support if directed by their peers (Cusack et al., 2004; Burns & Rapee, 2006; Jorm & Wright, 2007).

5.2.4.8 Diagnostic terminology

According to Link & Phelan (2001) the label of psychosis or schizophrenia can start the process of stigmatisation. The less familiar or stranger the behaviour is, the more frightening such behaviour becomes. Young people would have to draw on resources outside their own experiences to make sense of it, and hence start the process of stigma. A main resource in generating such processes would often be the media (Secker et al., 1999; Schulze et al., 2005).

During the ARFGS the use of diagnostic terminology did result in some separation and unfamiliarity, but the intention of using diagnostic terminology was to prevent stigmatisation. In the following extract, M showed her awareness of the importance of avoiding the use of derogative names:

> M: Be more polite though about the words used how some people would say oh your crazy like you're having a bad day you would say like you just feel down, it's like if somebody had a disability you would like not call them a certain word

The level of awareness displayed by M gives credit to the ability to use politically correct terminology and avoid the use of colloquial language such as crazy when trying to describe how someone is feeling. The positive ability for young people to demonstrate such awareness is significantly lacking amongst research studies that have only provided a very negative portrayal of young people's level of stigma through their use of language, which has been influenced by the media portrayal of psychosis, specifically using the terms of split personality, psycho and criminal violent imagery (Rose et al, 2007; Philo, 1996; Wahl, 2002; Wahl, 2003; Wahl et al., 2003; Wilson et al., 2000; King, 2004; Economou et al., 2014; 2012; Schulze & Angermayer, 2005; Angermayer & Malshmayer, 1995; Angermayer & Schulze, 2001). Hence, it is important not to assume too readily that young people are necessarily stigmatising or stereotypical in terms of their use of language.

Instead, M acknowledged the negative impact that colloquial terms can have on the individual, illustrating the positive reasons why diagnostic language can reduce stigma. These labels detach any element of personal failure or blame from the individual's behaviour, supporting the argument put forward by Wright, Jorm & Mackinnon (2012) that diagnostic labels create the sick not weak image. As a result, help-seeking behaviour increases. Whereas, Wright, Jorm & Mackinnon (2012) blamed the use of lay labels such as stress, paranoid and shy, for reducing the likelihood of seeking help.

The judgement of young people's level of stigma is based on an interpretation of specific terminology judged by professionals as inappropriate. More exploration is required of the context or meaning attached to such lay labels described by Wright, Jorm & Mackinnon (2012). Understanding how the use of diagnostic terms acted as a means of preventing stereotypical or stigmatising language from being used is an important consideration. This may not have captured a more private dialogue but, as M stated, this was a polite manner of describing the experience of psychosis, a publicly acceptable approach to discuss this topic sensitively. Thus, indicating that M may have entered the good participant role (Nichols & Maner, 2008).

Nevertheless, during both the ARFGS and PRFGS the term split personality was an acronym for psychosis. This has been a common finding when young people described psychosis from a Greek and German translation of schizophrenia (Economou et al., 2014; 2012; Schulze & Angermayer, 2005). These findings support the lack of intention of stigmatising the condition when using the term split personality. The term described the different behaviours and characteristics that individuals may display:

> C: Because they have got a split personality so in different situations, as in everybody, in different situations they behave differently so one minute they could be really nice and the other aggressive so
> R4: I've got for positive, multiple personalities. Because they could have, you know sometimes you don't like some people, and if they've got one or two nice personalities.

When considering young people’s views, including their use of terminology, one should be careful to not interpret their responses too negatively within a deficit-orientated framework to illustrate the need for anti-stigma interventions (Morgan & Ziglio, 2007). During the PRFGS, the use of less diagnostic terminology illustrated that young people could engage in a colloquial form of shared common language (Kirby, 1999; Burns & Schubotz, 2009). The result was that more personal meaning became attached to the condition, which allowed the young people to relate and empathise with the lived experiences of these individuals.

One could argue that an adult preoccupation of ensuring that young people use anti-stigma terminology is potentially a wrong priority taken in MHL interventions. It is therefore now important to turn our attention towards considering what the young people thought about the prospect of having a form of literacy to improve their understanding and knowledge about psychosis within the school environment. One main consideration would be to understand whether the young people believed that the aim of having this literacy should be anti-stigmatising or, as shown in this discussion, that such an approach mirrors adult concerns and worries.

5.3 Aim 2: To explore whether the concept of psychosis literacy is useful as the basis for educational interventions to improve young people's educational and health needs

There already exists considerable evidence to support the level of importance and interest attached to young people's views and opinions about their MHL (Woolfston et al., 2008; Armstrong, Hill & Secker, 2000). The flaw entailed within this evidence starts at how its foundations are held by adult professional-orientated concerns or aims/objectives. This means not starting on the premise that young people would necessarily agree to the implementation of a form of psychosis literacy within the school environment. It also means that the evidence potentially mirrors a great amount of adult-orientated assumptions about young people's own vulnerability. The value of using peer researchers is that it avoids such direction, and opens an alternative young person's perspective.

The diagram below provides an overview of the themes generated in my analysis that uncover the different approaches young people thought psychosis literacy should take and the rationale for their decision:

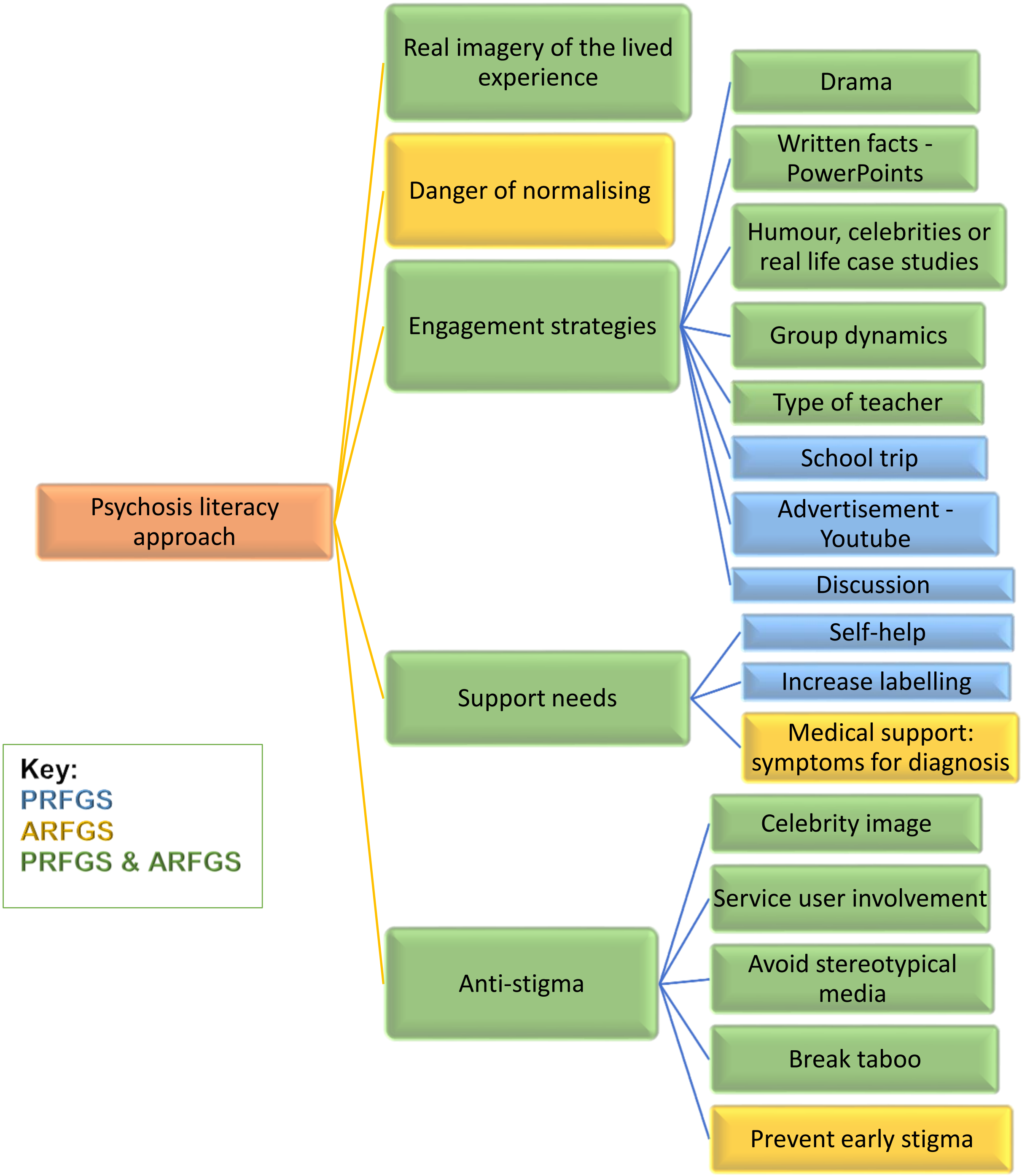


Figure 9: Psychosis literacy approach

From these themes, it is quite apparent that the PRFGS were less likely to mirror adult-orientated concerns about young people's vulnerability compared with the ARFGS. Each theme will now be explored in greater detail.

5.3.1 Exposure to shocking imagery - the reality of the lived experience of psychosis

During the PRFGS there was a strong theme that resisted the anti-stigmatising agenda proposed as a central aim of MHL (Jorm, 1997). Young people perceived an anti-stigma agenda as having the possibility of hiding the reality of an experience and projecting an image that the adult professionals want the young people to see. Instead, the truth about psychosis was preferred, without any attempt to downplay the severity of the condition:

> R1: shocking image would shock the children into understanding how much of a serious subject it is…show them more shocking images rather than having it sort of a touchy-feely attitude to the subject or shock them into realising how serious the subject is and that's very important to know about it

The young people felt that this imagery of psychosis would motivate young people to take this topic seriously and create a truthful image of psychosis which did not soften the cruel nature of the experience. This illustrates that the young people felt an anti-stigma agenda is untrustworthy, providing a plausible reason a focus on psychosis is ineffective if wanting to reduce stigma (Howard et al., 2008; Naylor et al., 2009).

The level of sensationalism involved in R1's response parallels the benefits the young people expressed in the soap opera characters that they had watched. However, this attitude goes against existing strategies used in MHL approaches when utilising contact with someone with psychosis. These existing approaches have used trained service users who have recovered from psychosis and portray a message intended to dismiss myths and enable the young person to relate to this individual (Rickwood et al., 2012; Pinto-Foltz et al., 2012). The problem with these attempts, from R3's perspective, may be the lack of trust that exists with these approaches, seeing through attempts made by professionals to reduce the stigma attached to the imagery of someone with psychosis.

The need to shock young people was a classroom management technique suggested to improve young people's level of attention, based on a concern that the literacy may not engage the individual enough:

> R3: But like people just shut up and sat and listened to them straight for two hours like I think its because like they actually have it and especially if its mental people might think don't say anything they might flip out.

The attitude taken by R3 about having contact with someone experiencing psychosis was one filled with fear and danger. One would have expected such feelings to be directly contrary to the rationale for supplying psychosis literacy within the school environment, as there is a concern that this will only further the stigmatising imagery of psychosis (Howard et al., 2008; Naylor et al., 2009; Amanas, 2008; Angermayer et al., 2004). The young people, instead, took an alternative perspective and viewed sensationalism not as a form of stigma or stereotype, but an effective means to sustain the young person's interest. The need to engage interest was a primary rationale for supporting the implementation of this literacy (see section 5.2.3).

The use of documentaries and soap operas were similarly a more useful and effective method:

> R2: I think that the getting the information from a documentary is reliable because its why they put it on TV and shown as a documentary it needs to be like true and objective so yes.
> Q: Like see on Eastenders can you remember like Jean off Eastenders, do you think that would be like a good way?
> R3: Yeah.
> Q1: Do you think that would be effective?
> R3: Yeah.
> R4: because our generation we watch everything and we listen to everything on through the media

The purpose proposed by young people was to achieve a form of literacy that supplied a real picture of the experiences of psychosis. It did not want to follow the lines of an agenda that tried to make it touchy-feely. The young people felt that they were resilient enough to face the truth and did not require protection from such imagery. This purpose does not fit Weare's (2004) concept of being emotionally literate, as the young people did not think the purpose of the literacy was to apply these experiences to the young people's own emotional wellbeing. It was entirely somebody else's experience or problem, which fits the agenda proposed by Jorm (1997), without the focus on helping to diagnose or help early help-seeking behaviour. The literacy was most beneficial in terms of providing an opportunity to freely discuss how psychosis may affect an individual.

Whereas, in contrast, existing media use in MHL approaches have focused on emphasizing the similarities that exist between someone experiencing psychosis and the young person audience (Saporito et al., 2011; Chan et al., 2009). These attempts may become mistrusted and instead possibly make young people more suspicious about what adults are hiding from them.

It was also important that the shocking elements of the experience of psychosis were explored during the use of drama productions. The reason put forward for this imagery was to scare young people to seek help and support:

> R2: You have to have being nasty as well in it and stuff, and that might like scare people to come forward.

This viewpoint supports the different views taken by boys in comparison with girls. The research evidence has illustrated that boys are less benevolent than girls, and they have showed less concern for their peer's mental health (Leong & Zecker, 1999; Burns & Rapee, 2006). This may reflect the difference in dialogue during the PRFGS, as there were more boys in the focus group sessions. The other possibility is that, without an adult present, the young people had greater chance to challenge, and present an alternative interpretation of, the values of having psychosis literacy (Grundy, 1996). Unlike the argument put forward by Ecclestone & Hayes (2009a; 2009b), the young people did not want the literacy to treat them as being vulnerable, but to value them as being mature enough for this level of exposure. This feeling reflects a social constructional viewpoint of young people as social actors, or as beings in their own right (James & Prout, 1990). This is illustrated in R1's discussion regarding what suitable age the literacy should be provided:

> R2: if you're really young some of the things like schizophrenia can be quite bad like some of the things people like like that would be a bit it would be a bit like I think shocking for a young child to see.
> R1: I know many eight-year-old boys who play on Call of Duty which is an 18 game, watch 18 rated movies, explicit music.

To confirm this thinking, there were also comments made when considering the level and nature of information to supply young people:

> Sa: A bit of both really like if you go into too depth too much depth it might scare some of the younger people say it was taught to older people in the same depth it wouldn't scare them as much because they are going to understand it a bit more because they are more mature
> M: Yeah make them fully aware no sugar coat it but don't hide
> C: Yeah be straight with them depending on the age
> L: if you are talking to 8-year-olds you shouldn't scare them but sort of our age it shouldn't be at all sugar-coated shouldn't be anything that's not there should be a clear understanding.

The concern expressed by M and L was that the literacy could be sugar coated in an agenda intended to be anti-stigmatising, and young people would be more likely to respond in this fashion in front of an AR (Burns & Schubotz, 2009). This supports the argument that young people's health educational needs should to be listened to without being satisfied that adults are deciding what is most right for young people (Schafer & Yarwood, 2008; Tones, Tilford & Robinson, 1990). The young people applied this concern when considering the prospect of a service user describing their experiences to the young people. There was a significant need expressed by the young people for the literacy to increase understanding of the lived experience of the condition, which involved a balance of the negative and positive aspects of the service user's pathway to recovery:

> B: No, I think you need to give the negative as well cause like the person who is doing it might have recovered but in a few years they might go back to the same state you just don't know you have to be made aware of that as well I think
> L: they can explain like their sordid past and stuff
> C: every person's case is a bit different
> Sh: Yeah it's a good thing like when they have recovered you can see their journey like not from suffering from it to getting it the worst bits of it to gradually getting better yeah look at it positively

Hence, by listening to young people's concerns, we can appreciate the importance of the meaning attached to experiencing psychosis. The concerns surrounding the potential dangers ascribed to the experience of psychosis is a valid and relevant issue that requires further exploration. Boys, for example, have been too readily criticised for their level of concern about the dangers associated with psychosis (Leong & Zachar, 1999). But in the context of this discourse the young people have supplied a justifiable rationale for the literacy not to neglect such discourse.

There were similar concerns expressed by the young people when considering the benefits of using video imagery, as it was important to allow young people to explore the lived experience of psychosis. This allowed the ability to appreciate how different individuals were able to cope and adapt their lifestyles:

> E: to follow one person like on a day out of their life like them going to work and stuff like that giving an insight into how they cope with it all
> H: I think it was really good to hear different people's stories so it just proves that everyone is different
> C: I think it was good to see rather than just the stereotypical, as they did not look stereotypical and I think it was good to get different people's point of views and what happened and how they found out and how to diagnose it

The benefit of portraying this image increased the ability for young people to appreciate how the condition affects day-to-day life, and helped them not become so focused on the stereotypical imagery of the condition. Thus, literacy interventions that have tried to only show a good and positive image of psychosis have neglected the holistic and diverse experience of psychosis young people want to understand (Saporito et al., 2011; Chan et al., 2009). During the PRFGS, this led to young people questioning the reliability of using media as a method, as you were unable to explore holistically the lived experience of psychosis:

> R4: but not everyone suffers the same things and has the same sort of conditions and things so its reliable in some sense but obviously you're not seeing the full story all the time, you're just seeing one person going through it not the whole disorder.

There was obviously more value placed on understanding the true lived experience of the condition than to worry about the extent to which such imagery would frighten young people. However, in most responses made by the young people, the use of media imagery or drama productions were criticised rather than praised in terms of the level of stigma and stereotyping generated from such imagery:

> E: it over exaggerates all the time
> R: I don't think it's very accurate because the media just shows stereotypical views and behaviours associated with them
> C: was kind of dramatic it wasn't realistic

This level of concern supports the mainstream of research evidence that the media negatively affects young people's level of stigma (Rose et al, 2007; Philo, 1996; Wahl, 2002; Wahl, 2003; Wahl et al., 2003; Addington, Berzins & Yeo, 2012;

Wilson et al., 2000; King, 2004; Economou et al., 2014; 2012; Schulze & Angermayer, 2005; Angermayer & Malshmayer, 1995; Angermayer & Schulze, 2001). The agenda of the literacy has therefore changed towards one that is concerned with reducing the level of stigma and taboo attached to experiences of psychosis. This fits more readily within the MHL approach and follows the need for literacy to primarily reduce stigma (Pinfold et al., 2003; Naylor et al., 2009; Chan et al., 2009; Saporito et al., 2011). This corresponds with the influence of the AR’s expectations, as media documentaries were only valuable if appropriate information explained the experience:

> E: but doesn’t really explain anything does it… follow one person like on a day out of their life like them going to work and stuff like that giving an insight into how they cope with it all day
> B: Yeah I think it’s just a bit basic
> C: it was only the voices

The value placed on the information that is provided is clearly important and reflects previous attempts made by literacy interventions to improve diagnosis and facilitate early help-seeking behaviour (Secker, Armstrong & Hill, 1999; Kelly, Jorm & Wright, 2007; Sakellari et al., 2011; Wright et al., 2006; Wright, Jorm & Mackinnon, 2012). It was not sufficient for literacy interventions to expose the lived experience of having psychosis.

In contrast, no concerns were raised during the PRFGS. Justification to explore the lived experience of psychosis made the content of the sessions dramatic and shocking. The reason for this difference stems from the demand characteristics placed on the young people to conform to the agenda set in the aims of MHL (Jorm, 1997). However, the lack of demand characteristics placed on the young people during the PRFGS enabled the young people to avoid a dialogue that satisfied an adult-orientated agenda.

The prospect of having contact with someone who had not recovered from psychosis was discounted as inappropriate during the ARFGS. This imagery would undermine attempts for the literacy to reduce fear and concern about psychosis among young people:

> Sa: some people may be worried about it may not feel comfortable around them

> L: You would have nightmares you can't bring out this scary person who is nuts
> L: And what would happen with the bad person in the room, no you can't have a scary murderer in there
> C: They come and sit next you and you are like woo and then literally I don't think I would say a word to them because I would be that frightened to trigger it off again

These concerns reflect the rationale put forward by earlier literacy interventions that have been more cautious in using contact as a method when exploring the experience of psychosis, as there was a belief that further stigma would develop against these individuals (Pitre et al., 2007; Penn et al., 1994). There have been more attempts to relate to the experience of individuals who had recovered or trained to reduce stigma (Rickwood et al., 2012; Conrad et al., 2009; Pinto-Foltz et al., 2011). The use of celebrities has been seen to particularly increase tolerance and empathy (Saporito et al., 2011; Couture & Penn, 2003; Pettigrew & Tropp, 2006; Corrigan et al., 2012). The level of young people's vulnerability was significantly higher within this dialogue compared with the PRFGS, showing that these views again mirrored the AR's concerns (Hallett & Prout, 2003; Foley, 2008; Morgan & Ziglio, 2007).

The implication of these findings supports Ecclestone & Hayes' (2009a; 2009b) argument that we should not create a therapeutic education that undervalues and problematises young people. This means that we should value young people's needs in their education and, in this case, the form of psychosis literacy was not therapeutic but informing and truthful. Young people valued the truthful realistic picture of the lived experience of psychosis. They did not view the usefulness of applying this knowledge to their own mental health wellbeing as suggested by Weare (2004). In fact, this was one reason R4 felt that such shocking imagery may not be suitable for certain young people whose first-hand experiences were related to the experience of psychosis:

> R4: I think some people might feel uncomfortable discussing it if they've had like personal experiences in their family or something where they've had a negative sort of experience with it so I think that would need to be taken into account that some people might find it sensitive issue but I don't think everyone would.

The young people therefore did not agree with Ecclestone & Hayes' (2009a; 2009b) argument that education should focus on traditional subject areas. On the other hand, during the ARFGS there was much more concern and worry directed towards the dangers of young people being exposed to such educational initiatives. In these arguments, we again see young people mirroring the adult concerns expressed by Ecclestone & Hayes (2009a; 2009b) that it could potentially end up problematising and medicalising young people's own behaviour. These dangers will now be considered.

5.3.2 The dangers of brainwashing – the school craze

These two terms, brainwashing and school craze, expressed concern and potential dangers of having psychosis literacy. First, we will examine what the young people meant by being brainwashed and how and why this was a concern.

Brainwashing was contextualised in terms of young people becoming easily persuaded and obsessed about themselves. These concerns reflect Furedi's (2004) argument that individuals are becoming increasingly passively narcissistic throughout their daily life. Young people automatically think that because they are receiving psychosis literacy, this will somehow affect them:

> M: they start to think that they have it they start to get it because they have seen it
> C: probably a part of yourself that will think I might have it I might have it and then you are absolutely convinced that you have it to the point where you are ill…like become obsessed at the fact that I've got it I've got it…it starts to drill in their heads that they have got it and then everyone will go mental and then they are not actually mental do you know what I mean
> R: people might think they have the symptoms might go seek help and so you get loads of people seek help and they don't necessarily have it

This theory generated by M, C and R goes against the agenda envisaged by MHL approaches to help young people receive appropriate help and support (Secker, Armstrong & Hill, 1999; Kelly, Jorm & Wright, 2007; Sakellari et al., 2011). The views support Ecclestone & Hayes' (2009a; 2009b) argument that such approaches could lead to young people problematising themselves inappropriately. Thus, supporting the argument that a focus on psychosis is not effective in reducing such stereotypes (Howard et al., 2008).

This argument continued when L and C expressed their concerns and worries on delivering psychosis literacy to young people who are not mature enough to use the information correctly at the ages of 11 and 12, where they were more likely to apply such diagnostic symptoms to themselves. This is supported by research evidence illustrating younger people's medical explanations of mental illness as being contagious, short-term and medically treated (Fox, Buchaman-Barrow & Barrett, 2008; 2010). The reason for this absence of literacy stems from younger people lacking exposure to mental illness and not understanding or knowing abstract diagnostic terminology (Inhelder & Piaget, 1958; Spitzer & Cameron, 1995). The consequence is the possible dangers of inappropriate self-diagnosis, which disagrees with the emotional literacy proposal (Weare, 2004):

> L: It could make people paranoid couldn't it because if you are learning about mental health you think oh my god I fit into that I've got some kind of schizophrenia I think if learning that sort of thing to 11-year-olds sort of mind then they might sort of assume that
> C: You don't know what they are thinking anyway yeah and I don't think it should be put into someone who is 11 or 12 because they are still learning other stuff and psychosis oh yeah 'I've got psychosis' but they don't
> C: if you drill the symptoms to a young person's head
> L: Paranoia

It was dangerous for young people to relate their own experiences with psychosis, as the young people thought that this would only increase the level of anxiety and worry among young people. This argument does not support previously discussed approaches that have promoted literacy interventions that encourage young people to relate to the experience of psychosis (Schulze et al., 2003; Seker, Armstrong & Hill, 1999).

There was also an alternative reason for concern if young people related to the experience of psychosis. This concern was based on the belief that it could turn out to be a school craze, associated with a cool, trendy image:

> L: Like a school craze
> C: Yeah do you know what I mean yeah I've got psychosis because she has got psychosis I want to be cool
> C: they will become obsessed that they have got it and think that they are cool because they haven't got the mental awareness of it

This idea reflects the pop psychology discredited by Ecclestone & Hayes (2009), in which mental illness has become normalised and interpreted within everyday life events. Whereas, in comparison, no similar dangers occurred during the PRFGS. The reasons behind such contrast lie in two potential areas. The first possibility is that the young people felt obliged to mirror adult concerns and worries related to young people's level of vulnerability and naivety (Barabasz & Barabasz, 1992; Morgan & Ziglio, 2007; Hallett & Prout, 2003; Foley, 2008).

The second possibility is that the AR focused specific questions to the young people about the possible negative consequences of having psychosis literacy, influencing young people's responses within this differential power relationship (Schafer & Yarwood, 2008; Bland & Atweh, 2007). The AR directed his questioning in a more negative manner to enable young people to question and challenge the adult's interests in favouring the implementation of a form of psychosis literacy. The AR did not want the young people to specifically feel that they had to accept such literacy. Whereas, the PRs did not specifically direct their questions towards the possible negative consequences of having the literacy. There was more ability for the young people to not feel that they had to be politically correct in how they approached their peers (Kilpatrick et al., 2007).

Peer research methodology has allowed greater insight into young people's own thoughts and views about themselves. A greater appreciation of the level of maturity credited towards how young people should be perceived has been exposed, which agrees with views that young people should be appreciated in their own right rather than understood as pre-adult becomings (James & Prout, 1990; Jenks, 1996). One could alternatively interpret PRs as lacking the relevant skills to ask balanced questions, resulting in a one-sided response (Kellett, 2010). Although from the young person's perspective there may have been no need to ask balanced questions.

Adult-orientated expectations placed on young people as vulnerable and needing protection continued when the AR asked specific questions about what they thought parents' views would be on the prospect of implementing psychosis literacy (Ecclestone & Hayes, 2009). The young people supplied responses of scepticism and caution:

> So: I think it depends on how they feel because if they have come across someone with psychosis and the bad effects of it they might be a bit wary of wanting their children get taught about it
> E: I think parents would be pretty like against it to start with because they will already have negative views from what they have experiences I don't know like they won't want their kids to sit in a class and have to go through it sort of thing if you get what I mean.
> M: Because children are meant to be innocent and you are meant to wrap them up in bubble wrap
> C: Cotton wool

There was an expectation that parents would be resistant to the provision of psychosis literacy to protect their children from the potential dangers of exposure to such experiences. The need to protect young people is a prominent theme within UK social policy that has created the belief that young people are dangerous, in danger and vulnerable (Hallett & Prout, 2003; Foley, 2008). The opportunity to discuss psychosis creates a great deal of apprehension amongst professionals (Howard et al., 2008). H offered a solution to this level of anxiety:

> H: Yeah I spoke to my Mam about it and she didn't understand what it really was until I told her because she had seen it on the telly and like Emmerdale and Eastenders and stuff like that but I think now she has a better understanding and she thinks it's a really good idea

The role of the young person has changed in terms of who has possession of knowledge in comparison with adults. H justifiably expressed concerns that parents are not a correct source of information, and that the school environment is the right environment to prevent inappropriate information.

One problem expected by the young people was the possibility that schools would be resistant in approaching the topic of psychosis literacy due to the school's religious perspective. L and M both reflected this barrier in relation to their Catholic school experience:

> M: some religious schools might be against it
> C: Probably Catholics
> L: Yeah there would be those against
> C: Our school probably wouldn't
> L: We never got taught about anything about mental health in our school so don't know if we were ever like
> M: We didn't get taught
> L: I don't know whether it was turned away from our school but you don't know do you
> C: Probably was

The reason Catholic schools would not want their children to engage in psychosis literacy interventions was not explained, but it may have been linked to the practice of Catholic schools prioritising moral wellbeing of their students separately from any outside interference. Further research into this plausible explanation is required.

In contrast, during the PRFGS there was notably less anxiety or concern about the prospect of young people engaging in discussion about psychosis. This confirms the effect that peer research methodology has had on interpretations of young people's level of vulnerability and naivety (Barabasz & Barabasz, 1992; Morgan & Ziglio, 2007; Hallett & Prout, 2003 & Foley, 2008). There was only one comment associated with how their parents would react to a discussion about psychosis:

> Q2: have you ever talked to your friends and family about psychosis?
> R4: Yeah because obviously I'm related to someone with mental health problems we talk about it sometimes but I don't know whether its easier to talk about that with them, I suppose it is because like they've sort of seen it and things but I don't think we take it that serious, like we don't every time we discuss it we don't often sit and have like a cup of tea conversation about how serious it is and how its a proper issue, sometimes we can just talk about it like everyday sort of context rather than having to just make it really meaningful but I don't think it happens like, kind of joking about with it or anything just sort of think its normal so we just talk about it normally.

R4's contrasting reaction illustrated a significant reduction in the perception of danger as the young people were able to engage in a less serious conversation about the experience of psychosis. The use of humour was again utilised to open dialogue about a sensitive topic. The dangers associated with brainwashing or developing a school craze reduced as the familiarity and normality of the experience increased. This supports strategies that have promoted the ability for young people to relate to the experience of psychosis (Schulze et al., 2003; Seker, Armstrong & Hill, 1999).

At the same time, young people proved their ability during the PRFGS to see potential dangers associated with the provision of literacy to young people if conducted inappropriately. This was illustrated when the young people discussed the dangers of the use of the internet:

> R3: I don't know because you get sort of like people who, the type of people who post like bad, like nasty things on the internet and they could sort of bring issues and be not very nice about it if you get me. So the people who do see it and they might think oh well
> R1: It doesn't really give a lot of useful information I don't think. Anyone can type stuff into the internet and its copyright, Wikipedia and stuff, anyone can just type anything they want to
> R4: Because like on Wikipedia anyone can put it on, do you know what I mean, so it depends what sites you're going

R3, R1 and R4 were concerned about the potential for the internet to misinform young people. This supported the argument that the use of the internet needed to be managed correctly. This did not suggest that the use of the internet was inappropriate or that young people were being brainwashed, but instead illustrated that young people are aware of the dangers of the internet and are not naïve as originally thought. However, views persisted about the naivety and vulnerability of young people during the ARFGS as the use of the internet was perceived as a greater danger and threat:

> M: they could go to Google and they might not be given the right information
> E: with other teenagers you get into arguments and then gets completely off topic and you get stupid discussions on there so I don't think blogging for anything is a good idea

The different views of the potential dangers of the internet are an important consideration that require review when considering what would be the right method to improve literacy. This is because the use of the internet receives greater criticism and discounts the potential benefits technology can have to improve access to relevant mental health support (Scott & Chur-Hansen, 2008).

Rather than a focus on the concerns of dangers that surrounded the literacy provided, during the PRFGS more focus centred on whether the literacy would be interesting or engaging enough for the young person.

5.3.3 Level of interest and engagement

The first potential problem raised with the use of documentary material was the length of time that a young person would be engaged in watching a documentary:

> R3: I think that it would depend because if you were going to like some people would benefit from like longer ones like if you were already interested and you said 'Oh yeah I'm going to sit down and watch this' then an hour like documentary would be fine but I think for everybody else it would be like just five minutes because otherwise you would switch off and there's only so much you can take in.

This concern reflects existing MHL approaches that ensured that the use of video material was short, including a fifteen-minute video 'The Same or Not the Same' (Chan et al., 2009; Pinfold et al., 2003). However, there were other similar interventions that showed a lack of concern about the length of the media that was involved (Naylor et al., 2009; Saparito et al., 2011). One needs to acknowledge supporting young people’s interest and engagement, rather than focusing solely on an anti-stigma agenda.

The use of drama productions, for example, were favoured by the peer participants as a method to increase the interest and level of engagement of young people:

> R1: I think it may engage them a little bit more but a production you won’t learn as much stuff as with a video
> R4: It would be a bit more interesting a way of getting it across
> R2: Yeah because it would be like entertaining to watch, and people would get information
> R4: Yeah cos everyone gets involved as well and like they get the audience

The entertainment value of such methods was an element not documented or discussed when considering the use of media as a means of improving young people’s literacy about the experience of psychosis. Instead, the focus was on supplying media images aimed at reducing levels of stigma which were professionally produced for this reason (Saporito et al., 2011; Pinfold et al., 2003; Naylor et al., 2009; Chan et al., 2009). Dramatised media imagery has been blamed for increasing stigma associated with psychosis (Wahl, 1992; Taylor & Gunn, 1999; Jorm & Griffiths, 2008; Angermeyer & Dietrieh, 2006; Wright et al., 2011). However, the young people in this dialogue have illustrated the benefits of the use of drama productions, which may be indicative of the changing role of drama to ensure that their productions are more educational and realistic in nature.

Media imagery was again credited during the ARFGS for avoiding written facts which were too boring, while media imagery allowed young people to take more notice to understand the condition:

> R: it’s sort of disguising the fact that you are trying to give information
> H: it wasn’t just throwing facts at you, you were actually understanding how it is real life not just how it’s in the paper.
> R: the fact there was Jo Brand at the beginning makes people more willing to listen to it because if she like recognised it and talked about it

The explanation provided by the young people is important in terms of increasing our understanding of what literacy approaches may be more suitable for them. This focus is often ignored from an adult professional perspective, where priority is given to viewing young people as empty vessels that need filling with information that is best for them (Watson et al., 2012; Jenks, 1996; Qvortrup, 1994). The result has been literacy interventions engaged in lecture presentations focused on dismissing myths associated with psychosis (Sakellari et al., 2014; Economou et al., 2011; 2014). However, in fact, these research findings support young people's dislike of having facts thrown at them, which could undermine the ability for school-based interventions to reduce the level of stigma by the provision of biomedical facts (Mellor, 2014).

Interestingly, R liked one media clip which had Jo Brand presenting the information. The use of humour and celebrity status allowed the topic to become less taboo and more openly discussed. R2 also agreed during the PRFGS that it would be more interesting if the person you were watching was someone that you might know:

> R2: it needs to be dramatic and it needs to have like not real case studies but like show people that you might know who are suffering from like an illness and you show that it does affect them but like not to the point where they become an outcast like

The use of celebrity imagery has noticeably helped to increase levels of tolerance and empathy among young people in earlier literacy programmes (Schmd, 2009; Couture & Penn, 2003; Pettigrew & Tropp, 2006; Corrigan et al., 2012). The insight of this evidence has shown that celebrity imagery has enabled the experience to be more recognisable and more interesting compared with real-life case studies. This correlates with the same feelings attached to the use of media, which increased their understanding of psychosis from a lived experience. It was more interesting and engaging to explore the wide-ranging effects of the illness on various lived experiences, leading to criticism against documentaries if they only considered one person's life story:

> R4: but not everyone suffers the same things and has the same sort of conditions and things so its reliable in some sense but obviously you're not seeing the full story all the time, you're just seeing one person going through it not the whole disorder.

This criticism is valuable to inform how literacy interventions can become more interesting and engaging for the young person. No consideration was rationalised in earlier media use within literacy interventions (Saporito et al., 2011; Pinfold et al., 2003; Naylor et al., 2009; Chan et al., 2009).

Valid questions about how a drama production could be conducted involved consideration of surrounding factors involving the type of group dynamics required to engage young people in their discussion about this topic:

> R1: A small group, I think it feels a little bit more personal, a bit more interaction between the cast or production
> R3: I think it would be a lot better if you showed it to a larger group. I wouldn't think that a few more isolated I think it would be more crowd, you probably take more from it, I think if you're in a smaller group you probably be more shy to show your opinions on it and stuff, I think that you need to find like somewhere in between because if its too big a group you don't feel like its personal to you

These comments show the debate that exists whether the literacy should be or should not be more personal. This relates to the rationale supported by Weare (2004), which suggests young people to be actively engaged in the drama and relate this to their own wellbeing needs. The level of caution expressed over the sensitive nature of discussing emotions within the classroom environment needs important consideration before implementing any form of psychosis literacy. The preference of smaller group discussion to protect confidentiality was supported by Kidger et al. (2009) but, as shown in R1 and R3's responses, the importance of promoting interaction and encouraging more engagement outweighed the need to protect confidentiality.

There was only one comment that questioned the level of bias documentaries can portray:

> R1: It's biased towards the negatives rather than the positives…they're trying to highlight what could happen, rather than what actually does happen.

This illustrates that, to the young people, it was more important for the literacy to be interesting and engaging than questioning the level of truth that surrounds the imagery of psychosis. Whereas, it was an expectation placed on the young people by the AR that they *should* be questioning the level of validity of the media, entering the good participant role (Nichols & Maner, 2008). Consequently, there was more freedom of discussion during the PRFGS to consider what would make drama productions more interesting for a young person audience:

> R1: I think it may engage them a little bit more but a production you won't learn as much stuff as with a video
> R4: It would be a bit more interesting a way of getting it across
> R2: Yeah because it would be like entertaining to watch, and people would get information
> R4: Yeah cos everyone gets involved as well and like they get the audience
> R5: it depends on the production, like if it's like really engaging and depending on who it's shown to then yeah it could be effective

The dialogue between R1, R2, R4 and R5 illustrated agreement that engagement and involvement were key features of a drama production that would make the literacy work. There was further praise during the ARFGS for drama productions to make the literacy interesting, as it could potentially be relatable and involved active participation:

> B: I think that would be quite a good idea because I've watched a drama at school and it was about a totally different thing but it really goes in I thought it was really good. It was about drink driving…were interested all the time because obviously acting it out and I just thought it was really good
> E: they are all going to pay attention to it and be interested in it because it is happening sort of in front of you it's something active happening rather than just than sitting down reading about it yeah
> S: it's interesting because all the cast are like teenage so it might like suit the audience but they always manage to get all the facts in and stuff on it so yeah

The young people reflected on previous experiences relating to the involvement of drama productions within the school environment which they enjoyed. There was also caution placed on these values, as they feared that young people may act inappropriately in response to the drama:

> L: If you tell an 11-year-old to act out schizophrenia you are going to get this extreme like extreme case of insane running around the room I don't think you could learn any fact about it

This mirrors expectations of young people's levels of being dangerous, in danger and vulnerable (Hallett & Prout, 2003, Foley, 2008; Morgan & Ziglio, 2007). The unexpected behaviour of young people acting in such an inappropriate manner was a worry in terms of whether literacy is suitable for all ages. This level of concern was also illustrated in previous research evidence that has expressed concern at implementing MHL for younger children due to their inability to understand diagnostic criteria, and their lack of emotional literacy and exposure to familiarity with mental illness (Fox, Buchanan-Barrow & Barrett, 2008; 2010;

Spitzer & Cameron, 1995; Johansson, Brumberg & Ericksson, 2007). Hence, during the PRFGS, there was concern surrounding at what age young people were able to understand the information provided:

> R2: A bit older, about fifteen, sixteen.
> Q: So why do you think those ages? Why do you think it's important?
> R2: You understand more, when your fifteen, sixteen.

This also involved a discussion about the level of maturity, and whether the young people would take the literacy more seriously:

> Q1: So how old do you think like, would it be okay if like somebody with psychosis to come in and speak to people?
> R2: Fifteen, and sixteen-year olds would probably be mature enough, but younger age groups are a bit immature.
> R3: by year ten or eleven you just take the piss out of them, you don't really listen to what's going on you just ignore it but if you do it when you're younger you kind of actually sit there and listen to what the teacher's saying and stuff
> R1: I've heard seminars in my old secondary school people would come in and discuss something and practically 99.9% of the students couldn't care less, if you introduce into the primary school maybe not sort of young as say year one but maybe like year four, five, six then it might sort of be integrated into the memories when they were young so they become more become used to it
> R2: Yeah because like it only happens more often like adults have it so like fourteen upwards

The main difference noted is the fact that the students were advocating for younger children to have psychosis literacy. This difference may be based on the argument put forward by targeted mental health programmes in schools to immunise earlier before later difficulties arise (Mernell & Gueldner, 2010). It was important that young people did not learn from an early age that mental illness is associated with personal failure and social exclusion of their peers (Kirkaldy, Eyserck & Siefan, 2004). Encouraging and addressing the problem of young people being unable to talk about their mental health wellbeing is important (Potts, Gillies & Wood, 2001).

The foreseeable problem with the proposal for earlier literacy intervention surrounds issues of maturity and the level of relevance this topic has for the young person. The existing PSHE association (2015) guidance only mentions specific mental illnesses within the Key Stage 4 curriculum, and the age of 15 was quoted by Bertolote & McGorry (2005) when advocating for these young people to be equipped to understand and deal with psychosis. There was a more prominent discourse during the ARFGS whether or not the young people were at the right age to be *interested* in being taught this topic:

> L: When they get older they start to rebel they might you know as you get older you don't really pay attention do you so like if you put it in 16-year-old lessons they are not going to get across whereas if you introduce it at 14 15 they are still going to be sort of listening to the teacher at that point so
> E: And at 15 and 16 you start choosing your GCSEs so you need to choose what you want to do, if they are not interested they are not going to choose

Thus, there was a different response and motivation that made the literacy potentially more suitable for a younger audience. This illustrates less caution among the young people about their level of maturity, and a greater desire and drive to increase interest among young people when suggesting different literacy methods. This is one area not given enough attention when considering what age to implement MHL, as it enables such an issue to be prioritised in a manner not considered before (Smith et al., 2002). One young person even mentioned the possible benefits of having school trips to increase awareness of psychosis and engage and interest young people:

> R2: Or even maybe going out to settings like in schools and taking students out to places like…obviously you'll probably need the parent's permission…But if like the parent's consent to it, then they'll be taking them out to places.

R2's main concern was the potential barrier that parents would not think the young person would be mature enough to be exposed to such school outings, although R2 did not clarify what type of trips he was suggesting. One suggestion could be a visit to a mental health hospital, which opens the possibility of collaboration between mental health services and schools.

One suggestion mentioned during the PRFGS was to use advertisements as a method of increasing young people's level of interest in the literacy provided. The rationale behind this feeling was in direct relation to their personal reflections on how it made them think and feel when exposed to a health-related advertisement:

> R: it was like this man and he walked into a room and it showed you like what he was seeing and it just showed that he was getting paranoid
> Q: And did you find that useful?
> R: Hmm well sort of sort of yeah

> R4: the way advertised in the media its better than any of the other methods because our generation we watch everything and we listen to everything on through the media
> R2: It depends how you get the information across like showing it on like a YouTube clip or like an advert on the side of your Facebook but probably more effective than showing it on TV and people just fast-forward the adverts or something
> R1: …seen an advert on strokes or whatever.
> R3: Yeah I like those adverts.
> R1: You like them?
> R3: Yeah.

This dialogue acknowledged the significance of the influence of advertisements. Rather than dismissing its influence in a negative manner, the young people illustrated the benefits such advertisement campaigns can have on increasing awareness and developing discussion on a topic. The influence of PRs created the ability for young people to personally reflect on their experiences and discuss more openly, honestly with personal disclosure (Kilpatrick et al., 2007). Even though such discussion was not related to classroom-based literacy interventions, the openness of such dialogue enabled the young people to open the discussion to relevant related issues with shared meaning between the young people (Kirby, 1999; Smith et al., 2002).

As shown by R2, the influence of the internet, specifically Facebook and YouTube, were more influential forms of advertisement than TV advisements. This is a key point to be aware of when considering the use of advertisements, as it is where young people are more exposed to this influence. It gives a chance to challenge and take more seriously factors and influences not given as much consideration before (Grundy, 1996; Smith et al., 2002).

R2 continued to favour the use of YouTube clips to sustain young people’s interest and engagement. The benefits of gaining the young person’s attention outweighed the caution held by questioning its validity and the dangers associated with the influence of the internet (Grundy, 1996; Kilpatrick et al., 2007; Kirby, 1999; Burns & Schubotz, 2009):

> R2: like a YouTube clip or like an advert on the side of your Facebook but probably more effective than showing it on TV and people just fast-forward the adverts or something.
> Q2: So xxx do you think that the internet is more like an unreliable source?
> R2: Not necessarily, possibly effective if something like is always there then like moving in the corner of the screen and like getting your attention and eventually you’re going to look into it.

In contrast, during the ARFGS, the use of the internet had potential to become a distraction from teaching:

> Sh: there are distractions like not everybody is going to do it are they end up on going on YouTube or something so yeah
> L: you are not going to get anyone who does that they are going to go on a game, no I don't think it would be effective

Sh and L's response doubted young people's ability to use the internet appropriately and gave a pseudo-teacher response. The reason for this contrast supports the benefits attached in not having to enter expected roles that young people normally enter when responding to an AR (Barabasz & Barabasz, 1992; Nichols & Maner, 2008). Moreover, rather than viewing the internet as engaging and interesting, it was criticised as boring in terms of having to read information from the screen:

> Sh: the internet it's just like a leaflet really but on the screen if you think about it
> So: they wouldn't really read it all like they wouldn't have time to read it all
> Sa: Same really, I get bored, I don't think I would read it to be honest and take it in
> L: you can give 16 17 year olds a piece of writing about it like an internet site to go and read like a fact file and they can take the information from it whereas if you give that to a 13-year-old they are not going to get through it

The reason for this response was because the young people were viewing the use of the internet as a teaching method in the classroom. This relates back to the original motives for MHL that have traditionally focused on aiming to improve recognition, diagnosis, and help-seeking behaviour (Secker, Armstrong & Hill, 1999; Kelly, Jorm & Wright, 2007; Sakellari et al., 2011). Whereas during the PRFGS, the aims of the literacy were not confined to such an agenda, and instead the use of YouTube and Facebook were considered more interesting and engaging to stimulate awareness and discussion outside of the classroom. The young people's first concern was that young people would not be interested or engaged in these literacy efforts, and this was the first hurdle that needed to be overcome before any literacy intervention would be effective.

In terms of the type of teacher used for the literacy, there was a further emphasis during the PRFGS about the need for the teacher to be engaging and interesting. The consequence of this primary concern disregarded the importance of expertise, which was considered to be boring:

> R2: How often do you sit in that theatre when someone was talking and take them seriously?
> Q2: What if it was like someone who knew what they were talking about?
> R3: But even when he talks about what he's chatting about, like nobody listens.
> R3: I personally think they can be quite boring.
> Q1: Why do you think they can be quite boring?
> R3: Because you don't want some highly qualified person teaching you all this complicated stuff, you want somebody your age talking you on quite a personal level rather than some person coming in like 'Oh look at me, I've got all these awards, I know what I'm talking about, listen to me' because I don't know
> R4: I'd prefer who'd been through it to come and teach it rather than a teacher who's just been to college and uni
> R3: I think it would depend on like the length and how they delivered it…if they're like not interested can just drift off and not pay attention if they don't make the speech interesting or whatever.

The young people wanted the teacher to be someone who you could personally relate to and ask questions about their own individual experiences, as this was what made the topic interesting for them. One can relate this with the feelings that young people expressed in favour of using peer educators for sex education to make their lessons more relatable, credible and relaxed, while not making them feel they were being lectured to (Forrest, Strange & Oakley, 2002). Whereas, the use of traditional teachers was criticised as lacking relevant training and being unable to explore the lived experience of real couples and real-life stories (Ellis, Pagarani & Fauth, 2009). The young people were able to comfortably question the level of authority individuals with expertise had (Bland & Atweh, 2007).

The level of interest and engagement when using service users supports earlier literacy interventions that have utilised contact with someone with psychosis (Pinto-Foltz et al., 2011; Conrad et al., 2009; Schulze et al., 2003; Pinfold et al., 2009; Chisholm et al., 2012). In these earlier literacy interventions, the motivation of personal contact was to make the experience more relatable to reduce levels of stigma. Instead, during these focus group sessions, it was the level of interest and engagement contact with service users brought that was the young person's main rationale, as illustrated in the young people's demands in Pinfold et al.'s (2009) study.

Nevertheless, young people did also acknowledge the importance attached to the use of contact with service users to allow young people to relate to their experiences. The focus on the emotional impact of the illness, and not necessarily the facts, was important for the young people to feel that they could engage, ask questions, and understand how this must affect their life. The aims of having such an influence fits into the agenda of improving young people's level of emotional literacy (Weare, 2004):

> R5: It's more personal, you can ask the person more questions and there's a lot more time for you to be able to talk to that person individually
> R2: start to think about things and like have questions you might like want answers to.
> R4: Its the same with we had a person who well a girl in our school, her brother fought in Afghanistan and he was while he was home for a couple of months and he came in our school and did a talk and everybody just sat and listened and because he had everybody just want to listen to him and find out what he had to say.

The young people's concerns, however, still centred on promoting engagement. R4 related to his experience of hearing the personal experience of a soldier fighting in Afghanistan, and this created a lot of respect and interest for R3. This method challenges the portrayal of boys as being less benevolent and showing less concern towards their peers (Burns & Rapee, 2006; Leong & Zachar, 1999). In fact, it is instead important to recognise the importance of how contact as a method of literacy can have a positive impact on boy's emotional literacy. From a male perspective the use of contact also had a positive influence on classroom management:

> R3: I think that would be good because when in school we were doing about crime and we had prisoners in from the prison down the road…But like people just shut up and sat and listened to them straight for two hours like I think its because like they actually have it and especially if its mental people might think don't say anything they might flip out.
> R1: everyone always remembers there's always one teacher in the school who they always fear almost and they would listen to, how they have the strongest character of all the teachers, have them help present it…to make the children listen and to understand this actually a very serious subject

Thus, when earlier research has condemned young males' preoccupation with the dangers associated with mental illness (Leong & Zachar, 1999), one can understand how this may be misinterpreted, as R3 and R1 commented on the benefits associated with levels of fear and danger to increase young people's interest and engagement.

In contrast, during the ARFGS there was much more concern about the level of expertise of the teacher. The reason for this concern was based on the belief that a lack of expertise would prevent explanation:

> H: I think it depends on the teacher, like the teacher might judge the child differently or if they explain it as just a psychological problem like we got taught it at school it was never it was always hearing things and was never explained properly
> M: Clear understanding like when someone asks do you understand and you say yeah yeah but you really don't, like when the teacher gets you to explain something
> R: Could you ask them questions
> L: Not when we had our sex talk
> L: I think it would definitely help out who talked to you about it, at school I couldn't stand when one of our teachers would have one of those talks with us because I just thought well you're a French teacher why are you talking to us
> L: shouldn't be somebody talking for hours it should interact with the people talking to more especially if it is small classes and it should be factual like they should not be talking about the stereotypes that they should not say oh you all probably thought this this and this that's patronising and it's a bit boring
> E: I think a mental health person or like somebody who has it because they will be able to explain it better and you wouldn't feel that they are just telling you what they have got off the internet or something because they have to teach you something about it
> L: I can remember when we were learning about drugs in school we got somebody who came in who had been through rehab and just to hear their story they weren't biased at all and they just wanted to stress the importance of it being talked about early on but just not a teacher it's just embarrassing

There are links made during this discourse to L's personal reflections on her experience of receiving sex education. In this context, the generic classroom teacher did not have the relevant expertise. The young people's concern in this context did not focus on keeping interest or engagement, but on the need for a teacher with expert knowledge. In this context the young people conformed to the MHL aims of ensuring that the correct information improved clarification and dismissed inaccurate information (Stuart, 2006; Chan et al., 2009).

The different views on the value placed on the expert could be interpreted from the influence of demand characteristics, as it is possible that the young people did not want to offend or devalue the AR's level of expertise. Nevertheless, overall there was a consensus that the influence of the teacher was important to increase engagement within literacy interventions.

The use of PowerPoint presentations was dismissed more readily during the PRFGS as being boring, and no positive aspects of this method were mentioned:

> R4: I'd say either because with a presentation you can probably be more interesting and listen a bit more…no more than five or six minutes because after that kids just tend to switch off and like mess about.
> R4: Oh death by PowerPoint
> Q1: So is that just a big no?
> R4: Yeah.
> Q1: Have you got any reasons for that?
> R4: College, when too many PowerPoints, and it's like it's terrible.
> R2: Yeah I think they're boring.
> R1: Like I say I find PowerPoints really boring so it doesn't matter who's doing the PowerPoint, even if they sing what's on the board it doesn't matter, its just boring.

These views were supported during the ARFGS based on the lack of attention resulting from the presentation:

> L: PowerPoint are inactive thing no one really pays attention to it
> Sh: the lesson on PowerPoint and we end up writing the whole everything on it write it all down and then you don't take any information in you just concentrate getting all down in time before she goes onto the next slide

The difference, however, was that the response given did not involve a categorical boring response. The young people did express the benefits that PowerPoint had in keeping interest when used appropriately:

> Sh: 10 minutes of a PowerPoint…then had a debate like a good mix
> C: good if there was someone there to answer questions
> E: I think PowerPoint can help but they give you like basics details but then people just shut off they get bored of them so because they go on for ages you just don't get 3 or 4 slides you get pages of them so
> L: Yeah it's good to have a sort of introduction to state the definitions which are necessary…because people might not even know what psychosis is

The young people were less likely to discredit this method since the AR created a PowerPoint for them with information about psychosis (Barabasz & Barabasz, 1992; Nichols & Maner, 2008). There remained consensus that young people did not appreciate it when too much, and too complicated, information was presented. This may show the possible reasons why the provision of biomedical information has not resulted in an improvement in reducing stigma (Penn et al., 1994; 1999; 2003; Mellor, 2014; Luty et al., 2007). Instead, as confirmed during the PRFGS, the young people favoured the provision of basic facts:

> R2: basic facts…general facts that everybody would understand

> R5: if its all like using like technical terms and stuff most common people when they like read it will just look at it and like not have a clue what it means and throw it away
> R1: they've just gave people a bunch of writing
> R4: Well you don't have to go completely into detail, you can just.
> Q: More making them aware of the existence.
> R2: Yeah make them aware of what it is
> Q: Like do you think would you like it taught in like any theory way at all?
> R3: No.

The level of young people's interest would reduce significantly using theoretical or technical language. One needs to recognise what affect language can have on young people's perception of mental illness, which was recognised to a certain extent by Fox, Buchaman-Barrow & Barett (2008), where the use of diagnostic labels did not help to convey meaning in comparison with the use of vignettes. Consequently, there have been arguments illustrating the lack of benefit in using the term schizophrenia (Wright et al., 2011). This highlights one of the main flaws in the ARFGS, where there was often an assumption that young people were aware of mental health terminology without questioning or exploring.

On exploration of the content of the basic facts young people felt they needed, multiple interpretations have evolved when taking time to listen to young people (Grundy, 1996):

> R2: It wouldn't just be that, it would be helpful to have you know any sort of difficulties or disabilities, we'd learnt about at some point.
> R1: but one that was kind of like statistical they gave you shocking facts about psychosis and how it affects people and all that kind of stuff, that would be something that would be more watched and talked about.
> R1: You want to know the treatment…A range of different symptoms.
> Q: Do you think it should be like positives or positivity towards it?
> R4: Yes positivity
> Q: Do you not think there ought to be sort of a, an equal view on it?
> R1: A balance.
> R2: Yeah I think there should be.
> Q: Give as much negative as there is positive?
> R3: Just tell you how it is.
> R5: You have to make it real…you have a true understanding of what it is, like facts and figures are just numbers you can't really gauge anything more meaningful from them.
> R3: Help people understand about like, real life situations doesn't it.

The meaning of basic facts was in fact quite broad in nature. Firstly, R2 felt that it would be inappropriate to just focus on psychosis, as knowledge about other conditions was also required, thus questioning the reductionist approach taken by the AR (Grundy, 1996). Whereas during the ARFGS, the focus on psychosis was unquestioned and accepted. Thus, young people do need to be genuinely listened to in order to find out what is best for their health literacy needs (Tones, Tilford & Robinson, 1990; Lindley, 2009; Dex & Hollingworth, 2012).

Within this dialogue, there was also a notable debate from the young people about how positive or negative the information should be, as R1 felt that statistical information would help stimulate discussion and shock young people about how serious the condition is. Whereas, R5 disagreed that statistics were useful, but instead wanted more meaning to be given to the lived experience. This debate proves the complexity of motives involved in the provision of psychosis literacy. There was no conclusive answer given, and we need to appreciate that the literacy supplied needs to respond to what R1 terms as achieving a balance. It is again important to realise that young people will appreciate and respond better to a form of literacy that gives them the ability to judge themselves and does not shy away from sensitive topic areas.

In relation to the use of leaflets as a form of literacy, the young people were overly critical of the extent to which such leaflets would be boring compared to the use of PowerPoint presentations:

> R1: But it's too much information, we don't really want to read them
> Q: So why don't, why does everyone think, who wouldn't read leaflets or information why do you think, why wouldn't you read them I mean? Do you think they're just boring or?
> R3: Sometimes.
> R2: just like the hand-outs in like if they just was like read this you wouldn't really take much in really would you?

The young people expressed the need for a good presentation, for information to be concise and for the leaflet to generate group discussion:

> R4: I think it's quite well presented, all the information that's just out there with all the details
> R2: I think that it's concise and that they are useful because everything is there.
> R4: if you've got a leaflet then you can sit with your friends and read it together and sort of talk over certain points in it or if you found a certain point you find interesting you can take that with you and say 'Oh what did you think of this?' and have it there as a reference but then obviously not everyone will use them in that way so I think it does depend on the people really.

The importance attached to stimulating group discussion around young people's views and opinions can be related to the benefits of using peer educators for sex education in generating small group work, with added time to clarify thoughts and ask questions (Lupton & Tulloch, 1996; Buston et al., 2001). The ability to give young people time to engage in such activities has not been prioritised in earlier documented literacy interventions.

Similarly, during the ARFGS the young people did not favour too much written information, which reduced engagement. They favoured a method that involved bullet points that presented the main facts of information, which consisted of medical information about symptoms, side effects, sources of support, the causes, and facts to reduce stereotyping from occurring:

> E: There is all too much writing with it as well you know it's just too much detail to you just want to be given the main points for it to get it done not sort of keep going on about it you know just dragging it out
> B: We thought there was too much writing in some of them like it's was just like too much people aren't going to sit there and read all that, rather just get straight to the point there was too much
> So: all the symptoms what causes it and… the different symptoms and medication
> Sh: the common side effects and symptoms
> M: How to get help
> L: how and where to get help
> E: given actual knowledge about it rather than them just seeing one aspect of it seeing one person in their worse state
> M: No bias
> L: Should talk about causes… there shouldn't be everything biased and then we went on to say what they should include that was causes and symptoms

The difference noted during the ARFGS was the way the facts the young people focused upon aimed to reduce stereotyping from occurring from a biomedical framework. There was less interest to increase young people's understanding of the lived experience of psychosis due to its subjective and personal nature not being seen as useful or factual enough:

> L: I don't think it was informative, it was interesting sort of as a case study it doesn't actually give you any information, don't think I would be confident in expressing what I know
> E: there is not enough like just personal views and stuff you would use
> L: there is no sort of like facts or statistics or anything like that to put in it that you could base anything on
> So: Might not be that accurate either you don't have accurate information whereas if you had like research you could be more accurate
> Sh: not enough detail to explain it to anyone

The value placed on the level of detail the young person wanted was paradoxical in relation to the earlier comments made that criticised the amount of written information. One reason for this is because the young people may not have wanted to appear not academic enough to the AR (Barabasz & Barabasz, 1992; Nichols & Maner, 2008). Therefore, it would be inappropriate to state that the young people found this type of information interesting or engaging, but instead they viewed it as necessary to please the AR.

The young people emphasised the importance of having an engaging and interesting leaflet, with nice presentation and structure. In this dialogue the young people particularly praised a comic-style leaflet in preference to leaflets which just had blocks of writing:

> L: That one's terrible just blocks of information…just like leaflets you pick up from the Dr's surgery which you just don't want to read you know they are just boring dull not many pictures they are just like who really wants to know about medication available it's just not necessary information.
> Sh: but a leaflet, here you go, you just chuck it in the bin when you get home if you are not interested then you probably won't read it much, if you are then yeah they are like probably attract more people to read them so presentation colours and stuff, so yeah
> E: just too difficult to read it could have been broken up a little bit easier
> H: didn't like how it was set out it's not easy to read it's a bit confusing
> L: I think it's comic book style and age appropriate, for day to day use not for specific or too difficult
> E: Yeah the way it is done like the flashy speech bubbles and stuff and all the pictures to go with it, it's more interesting to read

On the other hand, the young people still inconsistently expressed the need for the leaflets to hold enough detail and information to supply factual information about psychosis:

> So: It's got all the information like all the symptoms what causes it and things, and it's a good way to read about
> Sa: And the medication is there…still quite short…got questions about what people may ask if you have got brothers and sisters who have got it…
> L: because it's like written facts and figures it's actual information compared with our thoughts and opinions
> H: I don't know I don't think it gives as much information…it didn't have as much detail it's that sort of thing where it's related to one case again it's not like an overall view of it

Again, these comments are not related to generating interest or engagement but are requirements needed to inform young people about psychosis. There was a significant amount of concern expressed about the lack of concentration and attention that may occur from the implementation of the literacy:

> E: just shut off they get bored of them

> Sh: bit like people can easily just start day dreaming and not take it in
> R: If you haven't been listening or if it's not something that interests you or you don't think it relates to you then you wouldn't necessarily pay attention
> C: A lot of information at one go like I think if there are those people who don't concentrate anymore they just loose interest

These comments indicated that the young people were quite critical of their fellow peers regarding, firstly, to what extent they would be interested in actually receiving psychosis literacy, as the topic would not relate to them, and secondly the belief that they would not have the ability to retain the information delivered to them. Because of these concerns, the method of literacy needed to be more engaging:

> L: would be better if something was involves them… need to be like actively involved instead of just given the information
> Sh: get everyone to interact with it somehow
> So: I think drama would be a good way because you would be able to experience it and it's interactive so I think people would enjoy it more
> E: they are all going to pay attention to it and be interested in it because it is happening sort of in front of you it's something active happening rather than just than sitting down reading about it yeah
> R: you would be able to ask questions to the person who is delivering it
> C: I think if it's a lesson approach it gives it more chance for people to ask questions rather than a whole day one which when that day is over you are probably not going to get taught about it again

Whereas, during the PRFGS, there was less concern or criticism against the prospect of the young people not being interested or engaged in the literacy. There were only two outlier comments from R4, who expressed a preference to taking notes rather than engaging in discussion, and R5, who did not perceive that it was particularly important to discuss leaflets:

> R4: Take notes and things, not in a discussion.
> R5 I've never discussed a leaflet with anyone ever so I can't imagine its like a very common thing about but you never know.

This lack of criticism or concern shows no reflection of adult feelings surrounding young people's deficiency (Morgan & Ziglio, 2007). More credit should be bestowed on young people's level of interest and engagement, and their ability to express their strong views of what they want and need (Armstrong, Hill & Secker, 2000). Hence, it is inappropriate to jump to the conclusion that the literacy approaches should be dumbed down to make the literacy more engaging and interesting. However, there was still substantial preference expressed during the PRFGS towards utilising literacy interventions that were engaging and interactive, where the expression of different opinions and views could be explored:

> R4: talking about things that would be more likely to take it in if everyone was contributing to it then everyone's going to take something away from it rather than just watching and just decide to not pay attention if they wanted to.
> R3: Because all you have to do is look at the screen, look vaguely with it but you don't have to take anything in so yeah its better to like interact
> R4: I think its just as easy to switch off watching a video as it would do with someone stood talking to you that wasn't interacting with you sort of thing. If they were developed into a sort of context then you could have a couple of clips, I don't think putting a video on for the entire presentation would be a good sort of method.
> R4: obviously its just a bit of paper that you could put it in the bin if you wanted to, like some people might take the time to read it but if there's someone stood there directly talking to you about it then you're going to respond, you're not just going to sort of ignore their points and more likely to take something in from it

Overall there is overwhelming evidence during both the PRFGS and ARFGS that the literacy strategies suggested by the young people needed to increase young people's interest and engagement. The young people's suggestions on how this could be improved requires further exploration, and should not be side-lined when considering how to implement psychosis literacy strategies for young people.

The young people did not just think that the literacy strategies should be interesting and engaging, as there was a prominent theme that emphasised the need for the literacy to be able to direct young people towards suitable methods of receiving support. This was a more practical consideration of the aim of the literacy strategy, and not an educational approach to stimulate discussion and awareness. An analysis of these views will now follow.

5.3.4 To increase support

During the PRFGS, there was an acknowledgement that the provision of literacy could enable young people and others who they knew to be able to recognise and understand the personal experiences of psychotic symptoms. This first step would enable individuals to know how to react:

> R4: it could happen to you or someone you know and it sort of would help you learn how to deal with it and what to do in certain situations
> R3: just so that you could recognise it in yourself as well as the people close to you.

These views do support the agenda set out by MHL and mental health aid interventions. The main difference here from Jorm's (1997) definition is the lack of focus on needing intervention from outside professional (medical) support. The dialogue surrounded more self-help strategies and did not need or stress the importance of needing to receive a diagnosis as part of the help needed. This may show support for alternative meaning attached to psychosis, as illustrated in the service user movement who have challenged the dominance of psychiatry and expressed their dislike at the result that medication has done more harm than good on their lives (Monerieff, 2004).

Whereas, during the ARFGS the young people conformed to the traditional means of receiving medical support needed to name and recognise the symptoms of the illness to receive a diagnosis:

> So: I think if they get taught about it it would encourage them to get help because they will be experiencing the symptoms and like get scared and go and get diagnosed with it so they know what they have got and how to deal with it
> C: I think that if it's known it's not as fear about it and not a whole issue about going to the Drs and asking for help with it
> M: If you know about it then you would find it easier to recognise the symptoms and seek help if people know about it and understand it then it wouldn't be as big an issue
> L: I think when it's been explained if it's made clear what help you can get what type of help how to get it it would encourage them. Might be a relief for some people if that makes sense…it clarifies and prevents any confusion what they have got…I think it would make you better at recognising symptoms providing psychosis literature was informative

The importance of diagnosis was based on the need for clarification and understanding. This aim conforms to initiatives that have been associated with early intervention services within mental health, which is related to identifying young people with at risk mental health status (ARMS) (Yung et al., 1996). Hence the young people made the link of providing psychosis literacy with more targeted mental health programmes within schools. Kessler (2007) certainly illustrates how the prevalence of psychosis increases rapidly between the age of 15 and 17, showing the need to ensure that these individuals received early support in order that later difficulties do not become too problematic (Mernell & Gueldner, 2010).

So and C felt that without this form of literacy, a barrier would exist due to individuals being fearful and scared of receiving medical support. The undisclosed iceberg of the condition of psychosis among adolescences needs to be broken for them to know how to seek help, how to approach, and how to talk about their experiences (Potts, Gillies & Wood, 2001). Hence, a diagnostic biomedical orientated form of support could enable more targeted support.

This MHFA agenda promoted the ability of young people to identify and diagnose the symptoms of psychosis among their peers. This agenda was shared in the young people's feeling that the literacy provided was given to young people aged 12 from Year 7:

> E: Yeah because it's more common as you get a bit older, because you don't really find it in kids do you anyone with mental disorders and so if you are in a huge secondary school you are going to see other kids with it if you are in year 7 someone older that's got it you are going to see how it affects them so you ought to be taught about it so you know how to deal with it you know

Similarly, during the PRFGS the young people thought that an older age bracket of 15-16 was right for the literacy, as it would allow young people to help themselves and others understand the condition:

> R3: It's just a bit before the age when most people start sort of getting it.
> R3: So it could help you be a bit more understanding if anyone did get it.

There is no intention to diagnose these young people, as it was more important to recognise other individuals and enable young people to become more understanding of their condition. The reason for this difference was based on what was considered the best support for these individuals. From R3's perspective, to become more understanding involves considering what the individual feels is the best way to deal with their experience. The literacy approach should consider the diverse cultural dimensions involved when considering how to understand and support these individuals (Stone & Finlay, 2008; Nisha et al., 2005; Rahman et al., 1998). The young people have shown their awareness of the different nature of support needed, rather than focusing on a biomedical model.

However, when the young people responded to an AR, they were more likely to conform to the aims of improving levels of diagnosis and early professional medical support. This is because the young people would not want to appear to undermine the AR's professional position (Barabasz & Barabasz, 1992; Nichols & Maner, 2008). Thus, the importance attached to correct diagnostic labelling would help increase help-seeking behaviour (Wright, Jorm & Mackinnon, 2012). This made it important to improve young people's ability to identify psychosis, as the influence that the young people had on their peers to seek professional help has been identified as persuasive (Cusack et al., 2004; Wright et al., 2006).

If this was the reason a different response occurred during the PRFGS, it is a valid point to suggest that there is less perceived need or value in receiving a diagnosis from young people. This supports already building resistance under the PTM framework against medical intervention and increasing value towards the need to understand rather than just label the experience (Johnstone et al., 2018). These views also reflect aspects of Haslam & Kvaale's (2015) mixed blessing model, particularly the level of caution levied at the use of a biomedical model to explain the determining cause for developing a mental illness. This supports the need for the literacy to become more open-minded surrounding concerns about young people interpreted as illiterate based on their inability to conform to a biomedical diagnostic framework.

One needs to re-evaluate earlier research evidence that has used this biomedical criterion to discredit young people's illiteracy. The interpretation of inappropriate self-help for psychosis requires contextualisation (Jorm et al., 2008; Lauber et al., 2001; Kermode et al., 2009). Negative resistance to psychotropic medication may not necessarily illustrate illiteracy but instead show more knowledge base from the young person's perspective surrounding the negative side effects associated with such medication (Jorm et al., 1998; Priest et al., 1996). Finally, reluctance to use certain diagnostic labels and use of lay labels could be beneficial in terms of improving young people's ability to relate to the experiences, and should not always be interpreted negatively in terms of reducing the likelihood of seeking help (Wright, Jorm & Mackinnon, 2012).

There was, in fact, an acknowledgement by the young people during the ARFGS of the effect that a diagnosis can disinhibit individuals from receiving support as shown in the mixed blessing model (Haslam & Kvaale, 2015). The reason put forward by H involved the risks surrounding personal disclosure, meaning the diagnosis was considered detrimental to the individual's self-esteem:

> H: If you told your friends you might add to that paranoia that they have told other people then if you see other people laughing you might think that they all know like you don't really…The person is suffering from psychosis also has paranoia they see people laughing they might just add to it

H expressed concerns that support the pessimism involved in the lack of effectiveness of reducing levels of stigmatisation by focusing on the symptoms of psychosis (Howard et al., 2008). The process of recognising the symptoms of psychosis in yourself had potential to increase levels of paranoid feelings. Thus, the purpose of literacy could not form a source of self-help, but could make individuals more cautious and wary of the illness:

> R: they might treat them differently as if they have like they might talk to them more cautiously and stuff if they know more about them I suppose
> M if it was explained very badly then it might like add misconceptions

These thoughts support the reasons why certain literacy interventions have been cautious about how they portray the experience of psychosis to prevent inappropriate reactions from the young people (Pitre et al., 2007; Penn et al., 1994). There was concern from R and M about the nature of the content of the literacy provided. If young people know more about the illness, or if the information was explained very badly, there could be a greater chance of increasing social distancing, resulting in less support for these individuals.

There was even a comment made by R that believed the provision of literacy within schools could start to make young people ask questions why the school was providing this form of literacy. These questions could then lead to young people judging other peers' behaviours and think that one of their peers must have psychosis:

> R: I think they might be a bit weary because the kids or the students might be curious as to why they are being told about it and might start thinking that somebody in the school or college has it or something like that judging people

This feeling of judgement resulted in young people fearing that there was potential for bullying to occur. The reasoning behind these thoughts was the belief that the literacy would help identify these young people in the school:

> E: if you are sat in a class at school and you realise you are not going to say oh I'm going to the Drs about it because people will take the mick wont they and you will hear other people stereotyping or god I wouldn't want to

> know that person or that sort of thing so they won't want to go and want others to know that they have got it so it might either way encourage or not
> C: if they give information about it like people might like if like people are more aware of it people who are different might get noticed and it might cause like another kind of cloud like bullying in schools and colleges because of it

Marshall et al. (2005) supported the belief that young people are less likely to seek help due to a lack of trust, fear and stigma involved in receiving support. The context of such dialogue shows that the young people understood the provision of psychosis literacy to be within the world envisaged by Nind & Weare (2009), where schools need to address young people's emotional wellbeing needs. The context of E and C's dialogue exposed the problems involved in increasing levels of support if peers reacted negatively. To avoid this negativity, it was important that the content of the literacy should avoid severe imagery that would prevent a recovery image from developing:

> L: but if it's explained not badly but isn't explained fully then that would discourage people from getting help because if it's just explained the severe symptoms then I think it could put people off
> C: You imagine people thinking that I'm not going to get better, I'm not going to get better, and you imagine how probably there would be suicides

This reflects a key message in earlier literacy interventions to promote recovery strategies (Woolfstan et al., 2008). In this way, it was felt that there was more chance that young people would be more willing to encourage others to seek professional support (Cusack et al., 2004).

The use of leaflets, presented as a comic, was a positive source of support. It was effective in terms of how it had the ability to disguise itself as a source of information to enable engagement in discourse about the topic of psychosis. The importance attached to concealing information illustrates the level of young people's concern related to how embarrassing it would be to receive information about psychosis:

> B: it doesn't say on the front what it is so they are not going to be embarrassed about reading about it as well so I thought it was really good
> R: easily accessible…anybody can pick them up and look at them
> C: I think it depends on how leaflets are given out because if leaflets are given out in school like by your tutor or something like that like people might not look at them they may just put them in their bag and forget about them
> H: it would be bad because you can't ask questions so if you read it wrong or you don't really understand or you get the wrong impression you would be left with a horrible image in your mind of it still

> R: Yeah but I think they should just be given out and then they can choose whether they want to read it or not because if they just say take one if you are interested then people might be scared to take one in case someone sees them take one

Again, this supports the views put forward by Marshall et al. (2005) that there exists a lack of trust, fear, and stigma among young people in the prospect of receiving support. However, this level of concern was not as evident during the PRFGS, illustrating potential discrepancies involved in reflecting adult-orientated perceptions of young people's mental wellbeing (Dex & Hollingworth, 2012; Naylor et al., 2009; Armstrong, Hill & Secker, 2000; Sixsmith et al., 2007). The heightened level of danger associated with bullying and stigma gives young people less credit in their ability to support each other's mental wellbeing (Cusack et al., 2004).

Meanwhile, during the PRFGS more value was placed on being told the truth. The severe and shocking experiences of psychosis, detailed previously, would ensure that young people would take this condition seriously and gain the necessary support needed:

> R2: You have to have being nasty as well in it and stuff, and that might like scare people to come forward

Adult-orientated beliefs of young people's vulnerability may not allow literacy opportunities to motivate young people to understand the seriousness of the illness and emphasise the need to receive support and help earlier.

5.3.5 The anti-stigma agenda?

It was clear that throughout the focus group sessions one of the main outcomes expected from the literacy was to reduce the level of stigma attached to the experience of psychosis. There were, however, notable differences that existed between the PRFGS and ARFGS.

As discussed before, the use of celebrities was a method that could raise young people's level of interest and engagement. However, the benefits of using celebrities also included reducing levels of stigma. During the PRFGS, celebrities were seen as portraying a positive image of the experience:

> R3: someone that people look up to or someone like fairly well known with it who's like still liked or popular or something would be good because then people can be like oh well it doesn't have a bad effect on your life these people are still doing well or whatever

The level of hope generated by celebrity imagery was important for R3, as the imagery of psychosis became more familiar, comfortable, and relatable. This occurred in response to the presentation of the images of Madonna and Catherine Zeta-Jones, both with a history of mental illness:

Image 5: Celebrity imagery

This effect of being able to relate to mental illness has been well documented as an effective method to reduce levels of stigma (Secker, Armstrong & Hill, 1999; Schulze et al., 2005; Schulze et al., 2003). This was further supported by R2's response regarding the level of importance attached to having contact with service users who could relate to the young person in terms of their age:

> R2: I think like bore people if it's like an old man, if it's someone young and like relevant we're like more interested.

This correlates with research findings that have shown young people as being less willing to diagnose mental illness with their peers (Bowers et al., 2013), and were therefore more sympathetic to a young person's vignette than an adult's vignette (Secker et al., 1999). The motive behind R2's comment was not intended entirely to reduce stigma but focused on increasing levels of interest among young people, and not to bore them with imagery of older people.

Whereas, during the ARFGS there was more feeling that the use of celebrities would directly help in terms of increasing more understanding surrounding the experience of psychosis:

> C: I think if they used celebrities people would be more understanding and understand it more because they are seen as role models so if they state that they have a psychosis problem

The use of celebrities provided potential role models to enable young people to feel less anxious about the prospect of seeking support or disclosing their personal experiences (Potts, Gillies & Wood, 2001). H confirmed this effect as, in her words, it takes 'the edge off' a sensitive topic to enable young people to be able to relate to the experience. This dialogue fits an anti-stigma agenda, as H was concerned that young people would be influenced by negative imagery associated with psychosis:

> H: I think less frightened because most people know a little bit about it and it's mainly negatively they think it's hearing things and violence and stuff but if you were to watch the videos and stuff that we watched with normal people and sort of celebrities that we all know and know that they had it it would just take the edge off it a little bit

Favouring the ability for young people to relate to the experiences of psychosis resulted in a more familiar, less negative, and less pathological image (Schulze et al., 2003). There was no advantage held in focusing on the dangerous and unpredictable aspects of symptoms that would only increase levels of stigma (Wright et al., 2011; Jorms & Griffiths, 2008; Angermayer & Dietrich, 2006). The attractiveness of celebrity imagery would be a welcome challenge against the criminal and violent imagery often presented in the media (Wahl, 2003; Wahl et al., 2003; Wilson et al., 2000).

Paradoxically, however, H's concerns within this anti-stigma agenda also made H question the appropriateness of using celebrities:

> H: I'm not quite sure I don't know whether people will take it seriously like they might just think that people are being overdramatic like in the media when you hear about celebrities and eating disorders and stuff people just seem to sort of push it away and say aw that's just what happens so if it's I don't know just think people won't take it seriously you know

The pre-staged nature of using celebrities to combat stigma was linked to the often-criticised negative stigmatising imagery produced through the influence of the media (Rose et al, 2007; Philo, 1996; Wahl, 2002; Wahl, 2003; Wahl et al., 2003; Wilson et al., 2000; King, 2004; Economou et al., 2014; 2012; Schulze & Angermayer, 2005; Angermayer & Malshmayer, 1995; Angermayer & Schulze, 2001). H's response indirectly gives credit to the young person's ability to see behind the dramatic imagery of psychosis and identifies a problem of using such anti-stigma approaches.

The use of video productions increased the relevance of the experience of psychosis. L and R particularly felt that the media shown to them by the AR was useful because the actor used was a young female:

> L: Yeah I think a video would help you relate it to the person like say if it was the same age group as well you would be able to take it in more because you are interested like I don't think it would be as effective say it was a video case study about an elderly person who had Alzheimer's or something and you're a teenager watching it I don't think it would be yeah as effective you don't really feel for them
> R: I think it was good for keeping people engaged and like if I think it was quite good that she was a girl because normally you see a boy with schizophrenia

L's response is similar to R2's response in the PRFGS in terms of the importance of using young imagery to make the literacy more relevant to the young person. It was therefore important that literacy enabled young people to empathise with these individual's feelings and emotions:

> H: I quite enjoyed it I found myself engaged in and listening, it showed us how it affects her but put us in her shoes so I started to think of how I feel with voices and how I would cope I don't think I could

The ability to empathise with these experiences reduced the stigma that existed, as the gap between them and us reduced. Young people proved the same skills could apply to understand psychotic experiences, an ability previously discredited within anti-stigma interventions (Howard et al., 2008; Naylor et al., 2009; Saporito et al., 2011). The focus of these interventions avoided discussion about psychosis and chose to consider positive mental health or emotional wellbeing to reduce stigma (Potts, Gillies & Wood, 2001; Armstrong, Hill & Secker, 2000, Kidget et al., 2009).

However, young people in this research displayed less need to distinguish between mental health illness and mental health wellbeing, as they were able to understand and empathise with the links between the illness and the effect it had on an individual's wellbeing. The benefits of involving psychosis literacy interventions within an emotional literacy approach enabled young people to openly explore discussions on feelings, coping with emotional distress and accessing support (Kidger et al., 2009).

Consequently, the young people felt that to enable young people to relate to the imagery of psychosis, a stereotypical image should not be utilised:

> C: I think it was good to see rather than just the stereotypical, as they did not look stereotypical and I think it was good to get different people's point of views and what happened and how they found out and how to diagnose it

At the same time, the aim of building an anti-stigma image in the literacy should not necessarily mean that the image is sugar-coated. In C's response, she felt that giving a positive image of the experience would only build false positivity amongst the young people:

> C: What happens if someone in this room thought oh I'll have a positive outlook on it yeah they do have psychosis. But then what would happen if they don't have the positive effect of what they had

The literacy would therefore not prepare young people for the reality of the experience. This needs to be considered further when aiming to improve levels of effectiveness of such interventions, as it has been the primary aim when using media imagery to challenge levels of stigma that may be viewed as being deceitful to the real experience of psychosis (Pinfold e al., 2003; Naylor et al., 2009; Chan et al., 2009; Saporito et al., 2011).

C's response was exceptional, and in the main there was more concern during the ARFGS that the literacy should not overdramatise the experience when using such approaches. There was more potential that media could increase levels of stigma and discrimination through misunderstanding and inaccuracies:

> L: I think they would exaggerate it and take it to a whole new level and I think it's not really accurate way
> C: I think again it's a drama which is TV in a way I think if you are trying to express it there is a chance that it can get over dramatic because there is no other way that you could portray it than being over dramatic which could lead to people not understanding

> E: Yeah I think if you watch a play or a drama then you would see the stereotypical side of it again

This concern has been shared by most research studies that have blamed the influence of the media as a source of stigma for young people (Rose et al, 2007; Philo, 1996; Wahl, 2002; Wahl, 2003; Wahl et al., 2003; Wilson et al., 2000; King, 2004; Economou et al., 2014; 2012; Schulze & Angermayer, 2005; Angermayer & Malshmayer, 1995; Angermayer & Schulze, 2001).

The main priority overall emphasised the need to increase awareness and reduce levels of discrimination. The importance of increasing awareness was explained in terms of viewing psychosis as an experience that was not relatable and attached to someone else the young person may encounter during their lives:

> C: I think it is important because everyone needs to be aware of it because if you come across someone with it you don't want to kind of think they are mad do you know sort of thing, so I think everyone should have knowledge of it whether or not it's in-depth knowledge or not but yeah just be aware of it
> L: Yeah I think it should be put in the education system…because it increases the awareness I think you are going to come across it at some point like in your life anyway so I think if you start off learning in school it takes away that sort of fear that people have like or they have got mental illness like avoid them if you learn about it then you know the facts you won't have that hesitancy

Both L and C in this dialogue felt that it was important to take away the fear and avoidance that may exist if young people approached someone with psychosis. This illustrates the strength of young people's views on what they need and want about their literacy (Armstrong, Hill & Secker, 2000; Woolfston et al., 2008; Williams & Pow, 2007). The purpose of increasing awareness was related to a MHFA agenda. In this respect, blame and criticism pointed towards the current lack of provision of relevant psychosis literacy within the school curriculum:

> E: I definitely think so for that yeah, as in schools there is nothing at all you make assumptions about people you are not really told anything about them like how they act or behave so you start thinking up oh god they are going to be terrible but you know they might just be a regular person
> H: I think yes because there is a dark cloud over the subject so in schools they tell you like schizophrenia and stuff but they don't really explain it they just make out that it's seeing things and being angry and stuff

E and H expressed their concern about how young people would react to individuals experiencing psychosis. The fact that this topic was taboo could only lead to further stigmatisation, as young people may start fearing the unknown. This rationale for breaking the taboo was a reason parents may accept the provision of the literacy, which was related to the experience of parents feeling embarrassed about talking about sex to their children:

> L: when you talk about sex and stuff it takes the weight off the parents to explain it and stuff that's what my mam and dad thought, they thought it was good that it was being talked about

This ensures that young people's needs are not being trivialised by their parents, in the manner that young people have felt devalued in terms of their mental health wellbeing needs elsewhere (Dex & Hollingworth, 2012; Naylor et al., 2009; Armstrong, Hill & Secker, 2000; Sixsmith et al., 2007). The role of the school instead could provide a forum where young people could discuss and talk about psychosis with more freedom to allow young people to express their views as social actors in their own right, rather than pre-adult becomings (James & Prout, 1990). There was less emphasis placed on the need for teaching, but instead to value engagement of young people to discuss and break the taboo that surrounds psychosis:

> R1: I have a mental disorder myself and…I believe that more mental disorders and mental deficiencies should be taught more in schools or even colleges, its a taboo subject people don't talk about it, people don't want to talk about it, people don't want to know about it or know anyone with it…it needs to stop being a taboo subject. Cancer for example or different sexualities used to be taboo subjects and they're no longer now because they've been taught in schools, this is the same context, they need to be taught in schools. That's it.

R1's personal disclosure about his own mental health made him feel that more was needed to break the tension that exists in enabling discourse to develop. The use of PRs enabled R1 to talk more openly and honestly about a personal disclosure of his own experiences (Kilpatrick et al., 2007). R1 did not hold the same fears about the inappropriate reaction to the literacy provided, as his main goal was to simply allow a forum for young people to talk about psychosis. The simplicity attached to this motive has not obtained enough attention by earlier literacy interventions.

The choice of giving young people more freedom for discussion reflects the advantages of using peer educators for sex education. The advantages of this freedom were in response to the inability of teachers to break the taboo that surrounds this topic (Ellis, Pagarani & Fauth, 2009). Peer educators created more opportunity to clarify thoughts and ask questions (Lupton & Tulloch, 1996). R1 felt that this was the main reason topics such as cancer and sex are more openly discussed and related to without feeling ashamed or embarrassed (Forrest, Strange & Oakley, 2002).

The only exception occurred in a response from R4, who pointed out that this approach held more potential for increasing the level of identification and labelling process, as young people will notice more deviant behaviour and associate this with the experience of psychosis:

> R4: Just like what I said before some people are, they're scared of people because we could walk past people in the street, but it's just if they were pointed out people might start saying stuff, I don't want to stop understanding, I just want them seen if you get my meaning.

R4's response was still in favour of promoting literacy to increase young people's level of understanding. R4's concern was directed towards preventing inappropriate responses towards those experiencing psychosis. The young people instead wanted to increase awareness of the lived experience of psychosis.

During the ARFGS there was more rationale orientated around targeting literacy interventions to a younger age group to ensure a reduction in stigma:

> E: No I think college is too late by college you have already got those assumptions through the media
> L: I think 9 or 10 would be a good age as for this kids are more aware and I think that's about the age before rumours start going around kids they start getting sort of the media starts changing their opinions or giving them opinions I think that's the right age to talk to them

It was important that literacy was utilised to prevent misconceptions from taking root in young people's minds through the influence of the media. This conforms to the perspective that young people need to be immunised earlier before later difficulties arise (Mernell & Gueldner, 2010). This would ensure that from an earlier age young people do not learn that mental illness is associated with personal failure and do not socially exclude their peers (Kirkaldy, Eyserck & Siefan, 2004).

However, no such direction related to reducing stigma was present when the young people discussed the relevant age for literacy interventions during the

PRFGS. As mentioned previously, the young people directed their discussions related to concerns about maturity and level of interest. The negative imagery of young people's level of stigma and ability to stereotype stems from an adult perspective and may require re-evaluation to give more credit to young people's strengths, rather than focusing on their vulnerabilities.

5.3.6 Concluding observations

The rationale provided by young people to justify the need for the provision of a form of psychosis literacy differed because of the demand characteristics placed on expectations from an adult perspective.

Young people increased their peer's level of vulnerability as per the AR's expectations. Without an adult present, the young people were more willing to see the benefits of being exposed to the truth. The nature of this truth consisted of improving understanding of the real lived experience of individuals with psychosis, which became undermined by an attempt to focus the literacy within an anti-stigma agenda.

Responses during the PRFGS agreed with the argument put forward by Ecclestone & Hayes (2009a; 2009b) that these programmes should not make young people more vulnerable by encouraging a diminished self-imagery. Instead young people's level of resilience and ability to evaluate, judge, and understand information in its own right should be credited, and approaches should not feed young people selected truths to reduce stigma.

The consequences of creating a literacy programme designed to remove stigma increases the risk that young people will perceive these programmes with a greater level of distrust and suspicion. More questions may arise from the young people on what the literacy is trying to hide. A more open and honest approach has been called for to create an arena where young people can freely break the taboo nature of the topic. Paradoxically, focusing on more shocking imagery of psychosis created an essential step to expose and not shy away from such discussions.

In fact, when the young people focused on exploring the lived experience of psychosis, this resulted in an increased ability of the young people to relate to the experience of psychosis. Inadvertently this aim did have an anti-stigma effect within the dialogue engaged by the young people. This rationale supports the aims proposed by Weare (2004) in developing the emotionally-literate school. It has the potential to develop young people's ability to appreciate, understand and be inclusive when considering another individual's lived experiences.

In contrast, during the ARFGS there was more disagreement with the argument put forward by Ecclestone & Hayes (2009a; 2009b). The young people instead agreed that their peers were vulnerable, and that the purpose of the literacy should be to protect these individuals from the violent and aggressive imagery often associated with psychosis. The consequence was that the young people were apprehensive of the effect that literacy interventions could brainwash young people or develop a school craze.

The purpose of the literacy remained within an anti-stigma agenda to reduce young people's level of misunderstanding and promote a positive image of psychosis. The young people appeared to conform to adult anxieties when responding to adults compared with the PRFGS. This was most clear when the questioning used by the AR sought to explore what concerns they had regarding the delivery of such literacy.

The importance attached to Jorm's (1997) vision and aim that MHL should help young people to recognise, manage and prevent mental illness from occurring, differed depending on whether an adult was present. Under the influence of the AR, the support suggested was significantly medical-orientated, emphasising the importance of naming clinical symptoms to enable diagnosis. The focus of supplying a diagnostic and medical approach, as suggested by Jorm (1997), was lacking during the PRFGS and replaced by favouring community and social support. This supports the caution provided in Haslam & Kvaale's (2015) mixed blessing model that a diagnosis could become a barrier to receiving support under the premise of essentialist thinking surrounding biomedical explanations.

In fact, in contrast with these aims, it appeared that young people were more concerned with ensuring that the literacy programme was interesting and engaging. Interestingly this concern was rationalised differently when comparing the ARFGS and PRFGS. Concern was placed on having the right expertise to explain the literacy during the ARFGS, whereas during the PRFGS more importance was credited to ensuring that the literacy was taken seriously. To ensure it was taken seriously the young people felt that the literacy needed to be less boring and more relevant and relatable. This did not involve necessarily the level of information or professional expertise that was suggested during the ARFGS.

The contrasting views between the focus group sessions illustrate the conflicting nature of purpose between the aims set out by Jorm (1997), to increase knowledge and beliefs about mental disorders, and Weare's (2004) motives to create programmes in schools that develop young people's emotional literacy. The former motive correlates to the aims expressed to the AR, primarily endorsing and acknowledging the superiority of psychiatric knowledge as a form of truth against ignorance, stigma, and stereotyping. Whereas, the latter appreciates and understands that there is more needed than simply the provision of facts and information. Instead, young people connected emotionally when understanding the lived experience of such conditions. If this is not appreciated we run the risk of supporting essentialist thinking surrounding biomedical explanations of psychosis (Haslam & Kvaale, 2015).

Without an adult present, the young people were able to express their responses without risk of offending the AR or not conforming to the status quo to appear anti-stigmatising. This is valuable to understand how we can cater to young people's literacy needs more appropriately. Not learning to listen to the voice of young people has potential to become a barrier to successful health education initiatives, as professionals often become so preoccupied with their own aims and self-conviction of their own expertise that they forget that young people are experts of their own educational needs (O'Reilly et al., 2013). Critical pedagogy is an important practice that can help the application of literacy programmes to challenge and question the domination of psychiatry (Freire, 1968). The PTM framework creates an alternative challenging perspective on the experience of mental illness needs to cater to young people's literacy needs (Johnstone et al., 2018). An environment in which students and teachers learn together could help the approach needed for such a literacy programme, without assumptions of illiteracy and stigma degrading the value of the young person's contributions.

5.4 Summary of main points

Aim 1: To explore young people's understanding of psychosis

- Young people demonstrated their ability to understand psychosis as a 'problem of living' and not just symptoms of an illness. This social meaning has moved away from the pathologising assumptions made in the folk psychiatry model, and illustrates the potential of utilising the Power Threat Meaning Framework as a means of opening an alternative dialogue with young people.
- Young people were able to place psychosis within a wellbeing framework, which enabled the young people to relate to the experience of psychosis. This ability to relate moved away from othering the illness, and created more empathy and concern regarding psychotic experiences. This included the experience of hallucinations.
- In contrast, the young people during the ARFGS were more likely to enter the good participant role to please the AR. Hence, the dominance of psychiatry was more influential in terms of engaging in an academic debate about nature nurture causes of psychosis, which involved more dangers attached to genetics (eugenics) and the dangers associated with out of control behaviour.
- There was finally a difference noted in the diagnostic terminology used during the ARFGS compared with the more colloquial language that was used during the PRFGS. The effect of this different terminology was an increased ability to relate and create more personal meaning to the experience. The importance of less sugar coating, the benefits of soap dramas and the use of humour has opened an alternative meaning in exploring young people's understanding of psychosis.

Aim 2: To explore whether the concept of psychosis literacy is useful as the basis for educational interventions to improve young people's educational and health needs

- The young people during the PRFGS appeared to be passionate about the need to be provided with a real uncensored image of the lived experience of psychosis. Whereas, during the ARFGS the young people felt that such an image would be inappropriate and result in further stigma and stereotyping. In contrast, the PRFGS justifiably questioned the motives of a literacy approach that only showed a positive image of psychosis, as it would only lead to questions regarding what they did not want the young people to know.
- It appears that fears and concerns held against having psychosis literacy continued during the ARFGS through views that the literacy could brainwash or create a school craze in terms of young people thinking they have psychosis. The influence of the AR led the young people to possibly become expected to think of the worst case scenario in terms of the vulnerable image of young people.
- In terms of how the literacy intervention should be implemented, there was consensus among the young people regarding what strategies would be considered more interesting and engaging for the young person. This has created the opportunity to learn from the young people what would potentially work, and not necessarily what adults would feel would be appropriate or inappropriate.
- In relation to the motive of the literacy intervention there was significant discussion how it could both increase the level of future support for those experiencing psychosis and to reduce the level of stigma that exists about psychosis. The young people's responses to these aims however have question the traditional notions of providing MHFA, MHL or anti-stigma campaigns from a young person's perspective.

Chapter 6: Conclusion

In this closing chapter, the significance, limitations and recommendations of the different conclusions made during the research study will supply direction to future work in this area of research. The first question answered challenges the concept of viewing young people as illiterate surrounding the topic of psychosis.

6.1 Are young people illiterate?

Returning to the first questions posed at the beginning of this study, it is now possible to say that my results have challenged earlier notions of young people's illiteracy about mental illness. Firstly, this study has taken time to appreciate and explore what young people's own understandings exist on the experience of psychosis. From an adult professional interpretation, young people's literacy has at times been devalued inappropriately.

Young people's understanding of psychosis has its origins in a variety of different lived experiences, from personal contact to exposure to different media sources. From these diverse sources of information young people have developed their awareness of psychosis, dominated by concerns about the wellbeing of these individuals and concerns about their safety. Their level of literacy is multi-factored and should not be devalued as being simply stigmatising or stereotypical.

Young people have voiced a correct level of concern related to experiences of violence and aggression associated with psychosis. Young people have also had the ability to relate to the emotional impact of such experiences. From this interpretation, my results have contradicted earlier research results that have assumed that the experience of psychosis would not be relatable for the young person. In fact, the emotional wellbeing aspect of having psychosis was an area that young people were aware of and felt was an important aspect that needed consideration.

6.1.1 Biomedical explanation of psychosis

During the ARFGS there was noticeably more discourse that utilised diagnostic terminology of PTSD and depression. Moreover, the young people were keen to enter a debate orientated around the possible genetic causes of developing psychosis. The impact of focusing on a biomedical-orientated discourse resulted in an increase in the level of social distancing from the experience as something that could not be related to as a normal experience.

These results support Haslam's (2003; 2005) folk psychiatry dimension of medicalisation, as the experiences were not related to and they became established as abnormal within the field of psychiatry. While the level of moralisation of the individual's actions reduced, this did not outweigh the level of fear and anxiety still attached to such experiences supporting the mixed blessings model (Haslam & Kvaale, 2015).

The second point to make is that these results stem from adult influence on the content of discourse engaged with young people. The importance and value given to the biomedical model of mental illness follows the parallel value given in the world of psychiatry. However, without an adult present there is an alternative discourse and form of literacy that young people have perceived as more important and relevant. A discussion about this perspective will now follow.

6.1.2 The social meaning of psychosis

In general, during the PRFGS more social meaning was given to psychotic experiences. For example, the influence of being homeless and the blame levied against society's treatment towards these individuals in causing social isolation was highlighted.

The type of terminology used to describe psychotic experiences shaped the different response from the young people. The impact of general stress and feelings of being sad enabled young people to relate to psychotic experiences. The implication of this finding is contradictory to Haslam's (2003; 2005) folk psychiatry model, as the first step of pathologising did not take place. One should not necessarily assume or place psychosis solely within the field of psychiatry, as illustrated when considering the experience of talking to yourself.

6.1.3 Valuing young people's knowledge and understanding of psychosis.

This research has extended our knowledge of young people's literacy from a perspective not limited to a biomedical framework criterion. My findings increase the justification for not conforming to a biomedical criterion when judging young people's illiteracy (Jorm, 2000).

Instead, young people have shown their ability to relate to the lived experience of psychosis. This ability has been particularly valuable in terms of understanding how MHL strategies could reduce social distancing. When young people related to the emotional wellbeing of individuals experiencing psychosis the level of moralisation reduced.

This critical stance taken when interpreting mental illness illustrates significant parallels with the power threat meaning framework (Johnstone et al., 2018). Hence my results have supported the PTM Framework as a credible alternative to psychiatric diagnosis when exploring young people's knowledge and understanding related to psychosis. The social model of understanding the lived experiences of psychosis promotes meaning attached to personal recovery and increases the ability of young people to understand how psychosis influences the emotional wellbeing of the individual.

The present findings have served as a base for future research studies when trying to understand young people's level of literacy. This includes the need to re-evaluate adult-orientated preoccupation or assumptions attached to young people's illiteracy and the level of the stigma they hold. It did not confirm that young people were not stereotypical or stigmatising but partially substantiates that interpretations of literacy are far from straightforward. A more holistic and less judgemental criterion can offer further insight into how young people's knowledge and understanding changes according to the audience the young people are addressing when evaluating and appreciating young people's literacy.

One limitation of this study has however prevented a more detailed interpretation of young people's literacy. This limitation has been the lack of involvement of young people during the analysis stage of this research. The consequence of this lack of involvement is that interpretations of young people’s literacy are still within the judgement of the adult professional. More research needs to increase young people’s involvement in this analysis stage to develop a greater appreciation of young people’s views and opinions.

6.2 Interpretation of young people’s stigma

The conclusion made about misinterpreting young people’s level of literacy also applies when re-evaluating interpretations of young people’s stigma.

The result of young people utilising diagnostic labelling illustrated young people’s attempts to be politically correct and appear knowledgeable to the AR. These attempts, however, only proved to increase levels of separation and unfamiliarity on psychotic experiences. Nevertheless, the young people actively displayed a proficient level of awareness of the damage that stigma could cause when using inappropriate terminology. The young people chose to tread carefully and use politically-correct terminology to prevent any potential offence to the AR.

Whereas the use of PRs allowed a greater appreciation on how young people have been able to relate to the experience of psychosis, avoiding a traditional biomedical dialogue. Consequently, levels of separation and unfamiliarity reduced, as the young people attached more personal meaning to the experiences of psychosis. For example, dialogue elaborated upon the use of life stories from soap opera characters and documentaries which did not shy away from an exploration surrounding imagery of violence and aggression. Such a portrayal of psychosis, traditionally judged as stigmatising or stereotypical, revealed young people’s embedded concerns about the wellbeing of these individuals. From the young person’s perspective, to focus on the lived experience of psychosis did not intend to feed into any process of stigmatisation.

The results of this research illustrate that it is wrong to assume that more serious mental illness will necessarily be stigmatised by young people. The influence of culture and the use of everyday language needs further consideration when interpreting the context of dialogue used on mental illness. The use of humour, for example, enabled young people to engage in a dialogue about mental illness, and no intention existed within this humorous context to advocate being stereotypical.

6.3 Literacy interventions to reduce stigma

Since recommendations have suggested the need to re-evaluate interpretations of young people's literacy and stigma, it is only fair that young people should respond to how an anti-stigma agenda should influence the development of future potential literacy interventions.

The use of celebrities as a literacy strategy was one suggestion made during the ARFGS to help generate hope, reduce the belief of the severity of the condition and present an interesting portrayal of psychosis. The problem with this strategy however also involved the possibility that the use of celebrities would overdramatise the experience. During the PRFGS this anti-stigma agenda was not prominent, but concerns were related to displaying the lived experience of psychosis.

A consensus in both the ARFGS and PRFGS was that it was important for psychosis literacy sessions to allow young people the opportunity to discuss and talk about psychosis without worries about entering a taboo topic. The young people felt left in the dark about this topic, and lack of discussion only increased the level of fear and uncertainty attached to psychotic experiences.

The difference of opinion occurred on the value of the taught element of the literacy. More concern and anxiety was present during the ARFGS at the prospect of not being guided by professionals to avoid stereotyping and stigma from developing. Concerns were raised to the AR surrounding what methods of literacy would be most appropriate and age sensitive to prevent the danger of brainwashing occurring (the fear that they could have the symptoms of psychosis), or the prospect of popularising psychosis to the extent that it could develop a school craze. This held less worth during the PRFGS, as more trust entitled young people to discuss and talk openly about the topic.

6.3.1 Stop being 'wrapped in cotton wool'

One of the main contrary findings exposed in this research has been the expression from the young people during the PRFGS that they did not want to be wrapped in cotton wool by any form of literacy intervention. What the young people meant by this was that they had felt that anti-stigma interventions had prevented an exploration of the truth, due to feeling that adults have sugar coated or even avoided giving information to them. The young people wanted information to expose the lived experience of psychosis, to shock young people and make them take the topic seriously. This insight challenges traditional MHL aims preoccupied with reducing stigma at the possible expense of avoiding topics important and relevant for the young person.

An adult-orientated view of young people’s vulnerability has not necessarily catered for what the young people felt they needed. Recommendations from these results direct the need to increase trust and credibility through the freedom of discussion of ideas, sharing knowledge and understanding. Young people actively interpret and question the underlying motives health literacy may have. It is not simply the case that young people are fed with information and then accept what they are told. Results support the inappropriate focus in supplying biomedical information on psychosis to reduce stigma and stereotyping. Young people remained concerned surrounding levels of violence and aggression associated with the experience of psychosis. An alternative soft portrayal of this experience could be interpreted by young people as an effort to reduce the severity of the truth.

These findings are however subject to the responsibility for adult professionals to protect young people. The thought of giving more freedom within literacy strategies to discuss issues about the nature of violence associated with psychotic experiences is not likely to be an acceptable approach. The main limitation is the continued effect of young people being wrapped in cotton wool during opportunities of discussion within the school environment.

6.4 Literacy interventions to provide support

There was a consensus that literacy interventions should increase young people's ability to recognise and access the right help and support. The difference noticed was that during the ARFGS more focus and emphasis was placed on the need to supply a diagnosis to ensure that the support considered was medically orientated. Whereas, during the PRFGS potential problems acknowledged the application of a diagnosis in terms of increasing the risk of stereotyping and developing stigma.

The next main difference noted was the lack of emphasis on the importance of receiving professional support, which was not necessarily viewed as the only method available to enable personal recovery. Preference to a more social and psychological meaning within personal recovery avoided a clinical recovery meaning. The type of support young people needed to correlate with the integrated approach taken within the power threat meaning framework (Johnstone et al., 2018), challenging the traditional focus of explaining psychosis within a purely diagnostic and medically-orientated framework.

6.5 Exciting and interesting literacy

Results have shown that the appropriateness of literacy strategies changed according to whether the young people mirrored the AR's level of anxiety and concern around the strategies used. For example, the use of media as a method of literacy raised no concerns during the PRFGS. The criterion used during the PRFGS was based instead on whether the use of media would make the literacy exciting and interesting. The true lived experience of psychosis was what the young people were interested in exploring.

Whereas, during the ARFGS the criterion on increasing levels of excitement or interest was not as prominent as their preoccupation with the provision of correct information and the need to prevent a stereotypical image from developing to please the AR. For example, without an adult present the role of professionals were described as boring and the young people considered the potential benefits of alternative methods of engaging young people on a school trip. Similarly, the young people continued to remain dismissive of conventional strategies such as the use of leaflets and PowerPoint presentations as there was too much reading involved and not enough stimulation to increase interest or engagement.

Nevertheless, one common strategy praised was the use of contact with service users. The level of engagement and interest that this could supply was agreed, which adds to a growing body of evidence supporting the benefits of increasing service user involvement.

It is questionable however whether professionals would listen or appreciate such suggestions if the young person's priorities of ensuring literacy strategies are interesting and engaging did not correlate with the priorities set by the professional. Hence, it is possible that the young person's voice of what they perceive as important to increase engagement and interest will become overshadowed by what professionals believe young people need. For example, during the PRFGS the use of shocking imagery increased the entertainment and interest value of the intervention but remained attributed to sensationalism for the AR.

6.6 The influence of AR and PRs on mental health discourse

From a methodological perspective, the evidence from this research suggests that peer research changed the nature of demand characteristics on the young people. The result was that there was less need for young people to try and please or respond appropriately. The type of questions asked, and the resources used, created a dialogue not fixed within an adult-orientated agenda concerned with levels of young people's stigma and illiteracy. These dominating concerns in previous research literature have not allowed the young person's own voice to be valued.

These findings are significant as a base for future studies when considering the use of PRs. The influence of PRs has opened opportunities to explore a wider audience of young people not initially available to the AR and created a different social setting that opened a dialogue more colloquial in manner, and gave more evidence of personal disclosure.

Clear differences occurred between the ARFGS and PRFGS in terms of the social constructional understanding of psychosis previously neglected in earlier research studies. The implication of conducting a comparison of the data between these focus group sessions has increased the ability to substantiate evidence of how young people shape their views, ideas and understandings based on their audience.

The main limitation levied at the use of PRs was their lack of skills as researchers, which resulted in a certain level of intimidation and nervousness (see Appendix 8 for PR's reflection), the loss of research data and difficulties surrounding organising the focus group sessions. The PRs also remained directed by the AR's goals, and one should not assume that empowerment occurred. Nevertheless, the PRs acted very independently during the research training, developed their own research resources effectively and were even able to overcome obstacles about timetabling issues and recruitment.

Despite a high degree of anxiety surrounding the use of PRs throughout the whole research process, this should not be taken as a reflection on the ability or skills associated with the use of PRs. Alternatively, one should evaluate the benefits of using PRs in terms of what they can offer and achieve without an adult present, particularly in offering the opportunity to enter the young person's world.

6.7 Contribution to contemporary policy and practice

The DfE (2019, p36) has stated specific reference to pupils being taught *factual* information about the prevalence and characteristics of more serious mental health conditions. There has also been further commitment to build upon mental health awareness training and first aid to increase mental health literacy within schools (DH & DE, 2017). Despite these recent promising moves in policy, the importance attached to the young person's voice has remained deficient, which these research findings have sought to redress and have highlighted the complexity involved in catering for young people's literacy. This is valuable and needs further appreciation in current policy and practice if we want changes in the school curriculum from September 2020 to work successfully. This means further work in the development of NICE (2019) guidelines that are asking for further scoping evidence to support what universal classroom-based interventions will be most effective and cost-effective, and acceptable to the children and young people receiving them.

My research findings have challenged traditional approaches to delivering MHL within schools, and has utilised peer methodological approach to successfully expose a valuable insight into the different social constructs involved within the dialogue about mental illness with young people. This research has increased the involvement of young people as active participants in exploring this topic area. It has challenged existing theoretical frameworks of Haslam's folk psychiatry model, and instead understands how young people are able to relate to the experiences of psychosis, and has illustrated the application of using the PTM framework as a means of understanding young people's literacy. The position of young people's literacy has been valued against the notion of illiteracy. Through this process, this research has provided some suggestions of what type of literacy is needed to make it more relevant to the young people's needs and has a significant contribution to improve the future effectiveness of school-based mental health literacy interventions.

Appendices

Appendix 1: Recruitment PowerPoint presentation

PhD Research Topic:

Listen Up: Using young people's views to help shape education to support mental health

Teesside University

Teesside University is sponsoring this project for the purposes of research governance

Who is conducting this research?

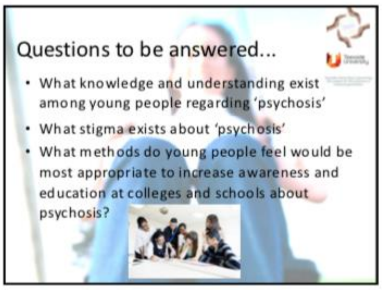
- Teesside University PhD student and Northumbria University Lecturer in Mental Health Nursing **Andrew Ramtohul**
- Conducted under supervision from **Professor Janet Shucksmith**, Assistant Dean (Research), School of Health & Social Care, Teesside University

Why do we want to do this work?

- Improve mental health education: gain accurate knowledge and awareness about 'psychosis'
- Change people's attitudes towards mental health
- Increase young people's voice
- We believe young people have a right to influence the future of their mental health education

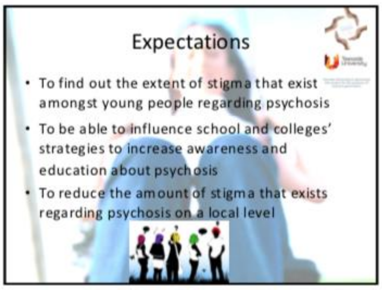
Research intention

- To promote young peoples' involvement i research
- To gain young peoples' perception of psychosis
- To increase psychosis awareness in schools and colleges



Questions to be answered...

- What knowledge and understanding exist among young people regarding 'psychosis'
- What stigma exists about 'psychosis'
- What methods do young people feel would be most appropriate to increase awareness and education at colleges and schools about psychosis?



Expectations

- To find out the extent of stigma that exist amongst young people regarding psychosis
- To be able to influence school and colleges' strategies to increase awareness and education about psychosis
- To reduce the amount of stigma that exists regarding psychosis on a local level

If you volunteer as a 'peer researcher' you will...

- Be able to be involved in a PhD study that can influence nationally
- Be able to refer to involvement in PhD research in your references for University
- Gain research skills
- Be trained as a 'Peer researcher': gain Certificate
- Gain confidence, people skills and opportunity to network with friends

Expectations of Peer researcher:

- Attend 3 pilot research sessions in college lasting 1 hour each over 3 weeks: **October/November**
- Attend 6 peer research training sessions over 6 weeks lasting one hour each: **December-February**
- To be involved in recruitment of young people aged 17-18 in research: **March**
- To conduct three focus groups: **April-May**
- 100% attendance and commitment required

Those interested...see me!!!

- You will receive an information pack detailing the nature of the research.
- Read through the information and talk about it with your parents/guardians/friends
- Please then inform me whether or not you are interested in participating by filling in the tear off slip within a week (first come first served)
- Thank you for your time

Appendix 2: Topic guidelines for semi-structured questions during focus group sessions with PRs.

First session:

1) Explore participants' knowledge and understanding of psychosis/schizophrenia
2) Explore where participants have gained their understanding of psychosis/schizophrenia and how useful/accurate they think it was
3) To explore social distancing with various individuals including someone with psychosis

Activity 1: Body mapping to explore the different knowledge they have regarding 'psychosis'/'schizophrenia': 20 minutes

Semi-structured questions to follow activity:

- What do you think psychosis/schizophrenia means?
- What are the signs and symptoms of having a psychosis/schizophrenia?
- What if any do you think are the differences between the terms psychosis and schizophrenia?
- What do you think are the causes of developing psychosis/schizophrenia?
- Do you think people can recover from a psychosis/schizophrenia?

Activity 2: Ranked post-it notes: Rank three sources where you gained your previous knowledge about psychosis?: 20 minutes

Semi-structured question to follow activity:

- In your opinion how accurate do you think the information you have about psychosis is accurate?
- Do you think more accurate and accessible information should be provided?
- Do you think schools/colleges should play an important role in providing information?

Activity 3: Vignette: 20 minutes

Semi-structured questions to follow activity:

- Are you worried or frightened about people who have a psychosis? If so what are your main worries?
- Do you think there is a lot of stigma or labelling attached to people who have a psychosis?
- Do you think that people with a psychosis could be looked after in their own homes?
- Do you think that people with a psychosis can get better?
- If Luke was one of your friends would you feel comfortable in supporting him and know what help he needs?

Second session:

1) To demonstrate the main signs and symptoms of psychosis/schizophrenia
2) To explore the variety of different psychosis experiences individuals can have
3) To use a variety of different media to explore the nature of psychosis/schizophrenia: PowerPoint slides with main facts, vignette of a young person who had suffered psychosis and media clips of individuals describing their experience of psychosis

Activity 1: PowerPoint presentation explaining what psychosis is (see Appendix 5): 15 minutes

Semi-structured questions to follow activity 1

- How useful was the information that was provided?
- Do you think that PowerPoint presentations are a suitable method in presenting this information to young people?
- What other information do you think is needed for young people to explain what psychosis is about?

Activity 2: Video clips from healthtalkonline and NHS choices websites: 20 minutes

http://www.healthtalkonline.org/mental_health/Experiences_of_psychosis/People/Interview/2405/Category/482

http://www.nhs.uk/Conditions/Psychosis/Pages/Introduction.aspx

http://www.nhs.uk/Conditions/Psychosis/Pages/George-and-Joshs-story.aspx

Semi-structured questions to follow Activity 2

- How useful was the information that was provided?
- Do you think that media presentations like these are suitable in explaining about psychosis to young people?

- What other information do you think is needed for young people to explain what psychosis is about?

Activity 3: Leaflets/website information about psychosis for young people (see Appendix 3): 20 minutes

Semi-structured questions to follow Activity 3

- How useful was the information that was provided?
- Do you think these leaflets/website information are suitable in explaining about psychosis to young people?
- Discuss how and why they are or not effective and suitable in providing awareness about psychosis for young people.
- What other information do you think is needed for young people to explain what psychosis is about?

Activity 4: Plenary Group quiz to dismiss myths that are present regarding psychosis (see Appendix 3): 5 minutes

Third session:

1) To discover young peoples' views of whether or not they think it is important to increase awareness in schools and colleges about psychosis
2) What resources could be developed to increase awareness of psychosis and illustrate how to support people young people know who may be displaying signs and symptoms of psychosis?

Semi-structured questions:

Focus group session discussion on "should young people have increased awareness about psychosis?": 20 minutes

- What are the reasons why you think it is important or it is not important for young people to have a form of psychosis literacy?
- Do you think young people would want some form of psychosis awareness and why?
- Do you think that having education regarding psychosis would encourage you or not to seek help if you were experiencing symptoms of psychosis? Why?
- Do you think improving your psychosis literacy would make you more vigilant regarding recognising symptoms of psychosis among your family and friends?
- Would psychosis literacy take away any misconceptions about the illness and affect how people with a psychosis would be viewed?
- Would knowing more about psychosis make you feel more frightened or less frightened regarding psychosis?
- What do you think parents and teachers would think about implementing such awareness in schools and colleges
- What age do you think would be most appropriate for such awareness to be given?

What are the best methods of implementing a psychosis literacy session for young people?: 10 minutes

- If sessions were implemented what would be the best method to increase awareness about psychosis to young people?

- Why do you think this method would be the best approach for young people?
- What information do you think young people need to know about psychosis?
- Where and how should the session be conducted?
- Who should deliver the session?
- Do you think schools/colleges have a responsibility to deliver psychosis literacy to young people or not?

Activity 1: To shower storm ideas how you would want psychosis literacy to be delivered to young people at your college: 30 minutes

- If you were in charge of delivering a psychosis literacy programme to young people, how would you design the programme? What suggestions do you have?

Plenary: Identify in discussion the common themes that have been produced by participants

Appendix 3: Vignette

Activity 4

Luke, 16 year old talks about psychosis

I was about 14 when it happened. I had a good family, did well at school and had group of good friends. Life had been good to me although my mum said I could not handle stress. I would be a bag of nerves before exams, was scared of failing and could not face is someone was unwell.

Uncle Rob's death a year back in the accident was just too much. I knew I would feel upset for a long time. But then I didn't feel upset. It was strange. I thought people were doing strange things to me like controlling me through radio signals. I felt I had lost control of myself and even felt my body was changing in a strange sort of way… not just the puberty. And then I could not face school, I was swearing, felt muddled in my head. My learning mentor got worried and spoke to my mum, who had noticed my strange behaviour. I couldn't sleep, couldn't be bothered about going out. I didn't like the idea of seeing a psychiatrist from the Child and Adolescent Mental Health Service and I thought they would judge me. But it was very different. She seemed to know and understand how I felt, what I thought. I felt relieved. She even said I was not going to be locked away in a hospital. It was just an illness for which I needed to take medication for few months or year. She then introduced me to Kay, a worker from Early Intervention Psychosis team. Kay explained to me and my family all about psychosis, what we could do to keep me well. She was there when I felt I was losing it before my exams. It's nearly a year now. I am like any other 16 year old, going to school, with friends etc... I take my meds and staying away from drugs and alcohol(The Royal College of Psychiatrists, 2012).

From the following statements please rank from the possible options the extent that you would feel comfortable or not:

0 = comfortable/no concerns, 1 = probably comfortable, 2 = probably uncomfortable/have some concerns, 3 = uncomfortable/have significant concerns

1) How would you feel about renting a room in your home to someone like Luke?

   0 1 2 3

2) How would you feel about Luke being a fellow worker in a job that you work in?

   0 1 2 3

3) How would you feel having someone like Luke as a neighbour?

   0 1 2 3

4) How would you feel about Luke babysitting your children for a couple of hours?

   0 1 2 3

5) How about having your children marry someone like Luke?

   0 1 2 3

6) How would you feel about introducing Luke to your best friend?

   0 1 2 3

7) How would you feel about recommending someone like Luke for a job working for a friend of yours?

   0 1 2 3

From the following statements please rank from the possible options the degree in which you would agree or not:
0 = agree, 1 = probably agree, 2 = probably disagree, 3 = disagree

1) If a group of former Mental Health patients diagnosed with psychosis lived nearby, I would not feel comfortable in going out on my own
   0 1 2 3

2) If a former Mental Health patient diagnosed with schizophrenia applied for a teaching position at a Primary school and was qualified for the job I would recommend hiring him or her
   0 1 2 3

3) One important thing about patients suffering from a psychosis is that you cannot tell what they will do from one minute to the next
   0 1 2 3

4) If I know someone who has suffered from a psychosis, I will be less likely to trust him or her
   0 1 2 3

5) The main purpose of mental health hospitals should be to protect the public from people who suffer a psychosis
   0 1 2 3

6) If a former Mental Health patient suffering psychosis lived nearby I would not hesitate to allow young children under my care to play on the sidewalk
   0 1 2 3

7) Although some patients suffering a psychosis may seem all right it is dangerous to forget for a moment that they are mentally ill.
   0 1 2 3

8) There should be a law forbidding a former Mental Health patient who has suffered a psychosis the right to obtain a shotgun license for hunting purposes

0 1 2 3

9) Someone suffering a psychosis should be blamed for their mental health problems

0 1 2 3

10) Patients suffering from psychosis can control their unusual behaviour and need to take more responsibility for their actions

0 1 2 3

Scales adapted from Link et al. (1987)

References

Link, B. G., Cullen, F. T., Frank, J. &Wozniak, J. F. (1987) The Social Rejection of Former Mental Patients: Understanding Why Labels Matter *American Journal of Sociology* 92 (6) 1461-1500

The Royal College of Psychiatrists (2012) Available from: <http://www.rcpsych.ac.uk/mentalhealthinfo/youngpeople/psychosisinyoungpeople/lukeandpsychosis.aspx> [accessed on 21 August 2012]

Appendix 4: Outline of Peer research training sessions

First session: The aim will be to review the findings that have emerged from the pilot focus group sessions. From the review, to consider how the research could be improved and what issues seem to be relevant to discuss in their research focus groups. What issues seem to be relevant to the young people and how could the focus groups be made user-friendlier for adolescents?

Second session: Reasons for conducting their research.

PRs start to create an information booklet to give to their participants, explaining the research aims and objectives. Why are they conducting peer research? Why are they considering the topic of psychosis literacy? What benefits and potential risks are there conducting the research?

Third session: Explanation of confidentiality issues.

Explain the importance of a ‘No names’ policy and not to discuss personal issues in the focus group, but focus on what other young people would want from having psychosis literacy. To respect diverse opinions and views in the focus group and maintain this confidentiality. To anonymise all data that is gathered. For the PRs to formulate an invitation letter and information sheet for the booklet to identify and explain all these issues to their participants.

Fourth session: Discuss appropriate sampling framework and size, and for students to commence scoping.

Explain who the PRs are going to approach to ask if they would like to participate in the research and reasons why they were chosen? The reasons why a mixed sex sampling approach would be appropriate (aim to gain a diverse range of opinions). The reason why 4-6 participants in the focus group would be an appropriate number, disadvantages of a large focus group. For students to then formulate an explanation of their sampling size and framework in their information booklet.

Fifth session: Discuss informed consent and develop consent forms.

Explain the importance of not placing any pressure or coercion on participants to participate and how this can be achieved. Give as much informed information about the research. Explain how participants can withdraw at any time from the research and allow time for participants to respond to the research and read information provided. Assess whether participants have the ability to give informed consent, and that they are comfortable to participate. PR to develop consent forms and ensure that these are signed and completed before participation begins.

Sixth session: Discuss how to engage a focus group and deal with potential problems with participants.

For participants to engage in role-play scenarios and how to appropriately deal with each situation:

1) Disclosures by participants, which would either cause harm to others or themselves. How to breach confidentiality and deal with Child Protection issues.
2) Participants stating inappropriate comments, which are deemed as aimed as causing offense.
3) Participants talking about confidential information about identifiable others and themselves.
4) Participants who become distressed during the research.
5) Participants who ask for more information or help that they cannot provide.
6) Dealing with participants who may cause disruption in the focus group.

Appendix 5: Powerpoint slides to guide professional ARFGS and PR training sessions

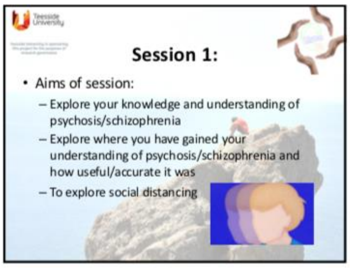
Listen Up: Using young people's views to help shape education to support mental health

Focus group sessions 1-3

Consent Forms….

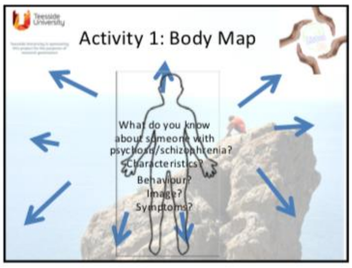
Our agreement:

- 1) Confidentiality: no personal information
- 2) No names: use no identifiable information
- 3) Respect other viewpoints
- 4) Don't talk over people: remember it is being recorded
- 5) Give everyone a chance to contribute



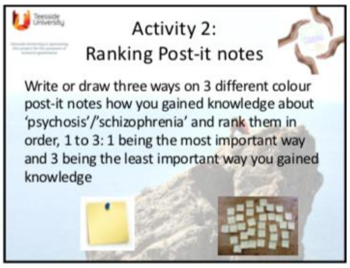
Session 1:

- Aims of session:
  - Explore your knowledge and understanding of psychosis/schizophrenia
  - Explore where you have gained your understanding of psychosis/schizophrenia and how useful/accurate it was
  - To explore social distancing



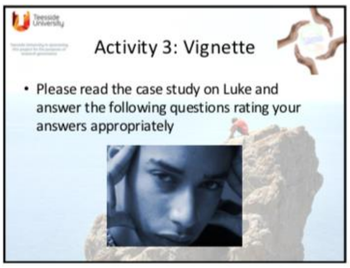
Activity 1: Body Map

What do you know about someone with psychosis/schizophrenia?
Characteristics?
Behaviour?
Image?
Symptoms?



Activity 2:
Ranking Post-it notes

Write or draw three ways on 3 different colour post-it notes how you gained knowledge about 'psychosis'/'schizophrenia' and rank them in order, 1 to 3: 1 being the most important way and 3 being the least important way you gained knowledge

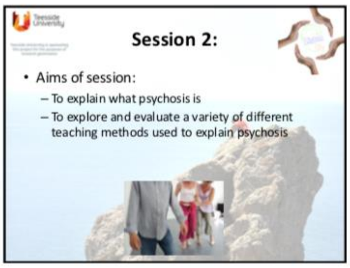


Activity 3: Vignette

- Please read the case study on Luke and answer the following questions rating your answers appropriately

What have we discovered today?
Five top points:

- 1)
- 2)
- 3)
- 4)
- 5)



Session 2:

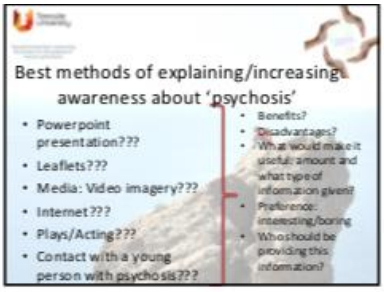
- Aims of session:
  - To explain what psychosis is
  - To explore and evaluate a variety of different teaching methods used to explain psychosis

Our agreement:

- 1) Confidentiality: no personal information
- 2) No names: use no identifiable information
- 3) Respect other viewpoints
- 4) Don't talk over people: remember it is being recorded
- 5) Give everyone a chance to contribute

Stand Up Activity

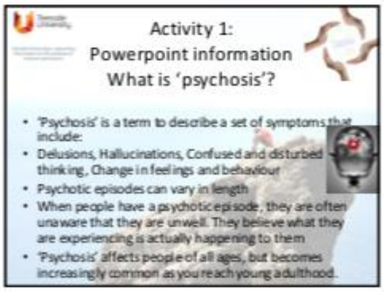
- Stand in a position which indicates whether or not you feel you have a good level of knowledge and understanding about psychosis from a scale of 1 to 10 (1 being least confident and 10 being the most confident)



Best methods of explaining/increasing awareness about 'psychosis'

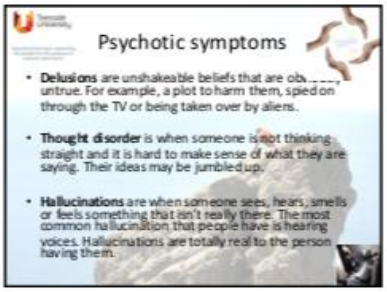
- Powerpoint presentation???
- Leaflets???
- Media: Video imagery???
- Internet???
- Plays/Acting???
- Contact with a young person with psychosis???

- Benefits?
- Disadvantages?
- What would make it useful: amount and what type of information given?
- Preference: interesting/boring
- Who should be providing this information?



Activity 1:
Powerpoint information
What is 'psychosis'?

- 'Psychosis' is a term to describe a set of symptoms that include:
- Delusions, Hallucinations, Confused and disturbed thinking, Change in feelings and behaviour
- Psychotic episodes can vary in length
- When people have a psychotic episode, they are often unaware that they are unwell. They believe what they are experiencing is actually happening to them
- 'Psychosis' affects people of all ages, but becomes increasingly common as you reach young adulthood.

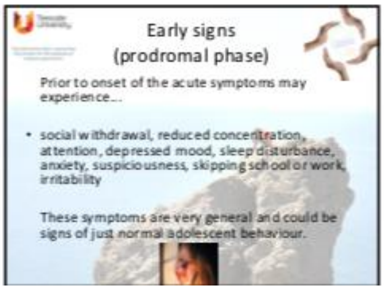


Psychotic symptoms

- **Delusions** are unshakeable beliefs that are obv..., untrue. For example, a plot to harm them, spied on through the TV or being taken over by aliens.
- **Thought disorder** is when someone is not thinking straight and it is hard to make sense of what they are saying. Their ideas may be jumbled up.
- **Hallucinations** are when someone sees, hears, smells or feels something that isn't really there. The most common hallucination that people have is hearing voices. Hallucinations are totally real to the person having them.

Other symptoms

- **Feeling**: Sad/irritable, isolated, confused/puzzled, lack trust,
- **Behaviour**: Difficulty sleeping, neglecting appearance, avoiding contact, behaving aggressive, little display of emotions, not speaking very much, decreased ability to initiate tasks, lowered levels of motivation or drive



Early signs
(prodromal phase)

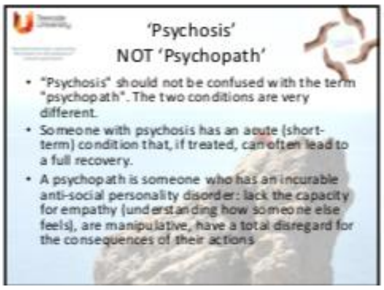
Prior to onset of the acute symptoms may experience...

- social withdrawal, reduced concentration, attention, depressed mood, sleep disturbance, anxiety, suspiciousness, skipping school or work, irritability

These symptoms are very general and could be signs of just normal adolescent behaviour.

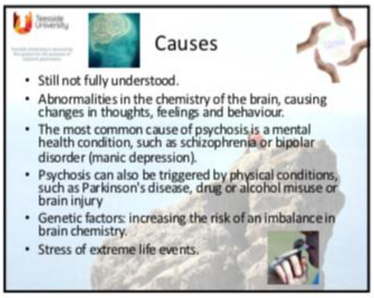
When can you have the symptoms of psychosis?

- Symptom of schizophrenia, bipolar disorder and schizoaffective disorder.
- Symptom of dementia, some forms of personality disorder and Parkinson's disease.
- Drug and alcohol abuse (Drug induced psychosis) and side effect of some types of medication.
- Triggered by severe stress or anxiety, severe depression or sleep deprivation.
- Puerperal psychosis (postpartum psychosis) can occur to women after 3 to 7 days of giving birth



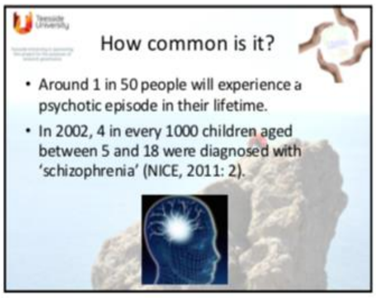
'Psychosis'
NOT 'Psychopath'

- "Psychosis" should not be confused with the term "psychopath". The two conditions are very different.
- Someone with psychosis has an acute (short-term) condition that, if treated, can often lead to a full recovery.
- A psychopath is someone who has an incurable anti-social personality disorder: lack the capacity for empathy (understanding how someone else feels), are manipulative, have a total disregard for the consequences of their actions



Causes

- Still not fully understood.
- Abnormalities in the chemistry of the brain, causing changes in thoughts, feelings and behaviour.
- The most common cause of psychosis is a mental health condition, such as schizophrenia or bipolar disorder (manic depression).
- Psychosis can also be triggered by physical conditions, such as Parkinson's disease, drug or alcohol misuse or brain injury
- Genetic factors: increasing the risk of an imbalance in brain chemistry.
- Stress of extreme life events.

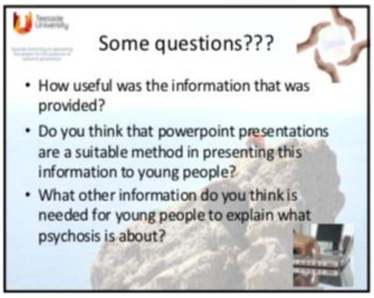


How common is it?

- Around 1 in 50 people will experience a psychotic episode in their lifetime.
- In 2002, 4 in every 1000 children aged between 5 and 18 were diagnosed with 'schizophrenia' (NICE, 2011: 2).

What help can be given?

- May not notice that there is a problem and deny that there is anything wrong.
- GP or school nurse can give good advice.
- Psychiatrist may find out whether or not they are ill and to offer the treatment required.
- Medication is an important part of treatment and often needs to be taken for a long time in order to stay well.
- Patient and their family need help to understand the condition, to cope and prevent the illness recurring.
- Support to rebuild confidence to continue with school, college or work.
- May need admission to hospital.
- Talking treatments can be helpful.

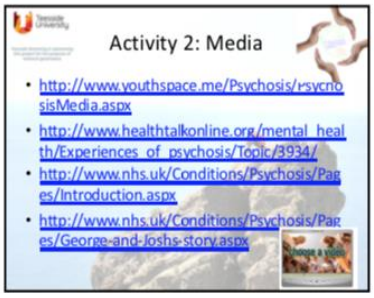


Some questions???

- How useful was the information that was provided?
- Do you think that powerpoint presentations are a suitable method in presenting this information to young people?
- What other information do you think is needed for young people to explain what psychosis is about?

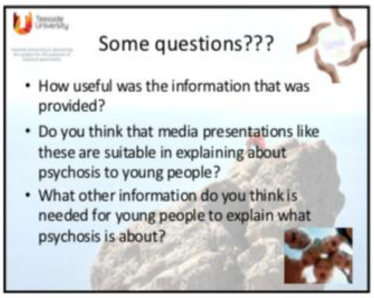
Stand Up Activity Revisited

- Now do the same activity as before – has your confidence changed?



Activity 2: Media

- http://www.youthspace.me/Psychosis/PsychosisMedia.aspx
- http://www.healthtalkonline.org/mental_health/Experiences_of_psychosis/Topic/3934/
- http://www.nhs.uk/Conditions/Psychosis/Pages/Introduction.aspx
- http://www.nhs.uk/Conditions/Psychosis/Pages/George-and-Joshs-story.aspx

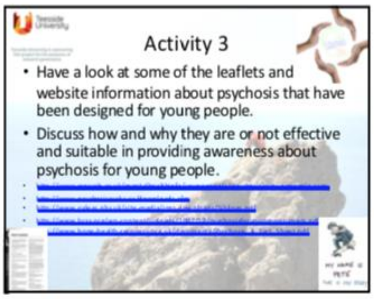


Some questions???

- How useful was the information that was provided?
- Do you think that media presentations like these are suitable in explaining about psychosis to young people?
- What other information do you think is needed for young people to explain what psychosis is about?

Stand Up Activity Revisited

- Now do the same activity as before – has your confidence changed?

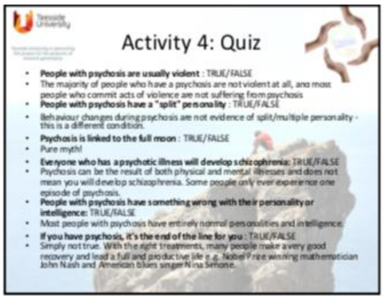


Activity 3

- Have a look at some of the leaflets and website information about psychosis that have been designed for young people.
- Discuss how and why they are or not effective and suitable in providing awareness about psychosis for young people.

Stand Up
Activity Revisited

- Now do the same activity as before – has your confidence changed?

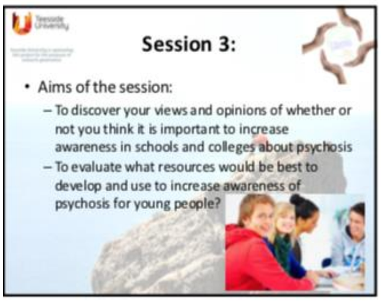


Activity 4: Quiz

- **People with psychosis are usually violent** : TRUE/FALSE
- The majority of people who have a psychosis are not violent at all, and most people who commit acts of violence are not suffering from psychosis
- **People with psychosis have a "split" personality** : TRUE/FALSE
- Behaviour changes during psychosis are not evidence of split/multiple personality - this is a different condition.
- **Psychosis is linked to the full moon** : TRUE/FALSE
- Pure myth!
- **Everyone who has a psychotic illness will develop schizophrenia:** TRUE/FALSE
- Psychosis can be the result of both physical and mental illnesses and does not mean you will develop schizophrenia. Some people only ever experience one episode of psychosis.
- **People with psychosis have something wrong with their personality or intelligence:** TRUE/FALSE
- Most people with psychosis have entirely normal personalities and intelligence.
- **If you have psychosis, it's the end of the line for you** : TRUE/FALSE
- Simply not true. With the right treatments, many people make a very good recovery and lead a full and productive life e.g. Nobel Prize winning mathematician John Nash and American blues singer Nina Simone.

What have you discovered today?

Write two discoveries on a post-it note to stick on the board as you leave:



Session 3:

- Aims of the session:
  - To discover your views and opinions of whether or not you think it is important to increase awareness in schools and colleges about psychosis
  - To evaluate what resources would be best to develop and use to increase awareness of psychosis for young people?

Our agreement:

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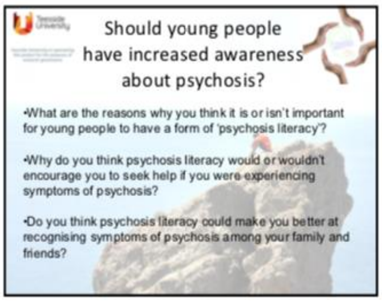
- 3) Respect other viewpoints
- 4) Don't talk over people: remember it is being recorded
- 5) Give everyone a chance to contribute

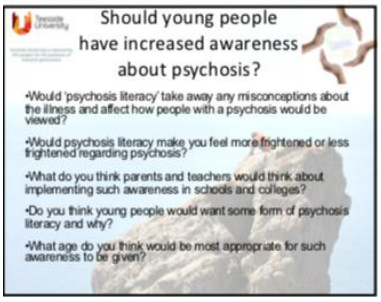


Should young people have increased awareness about psychosis?

•What are the reasons why you think it is or isn't important for young people to have a form of 'psychosis literacy'?

•Why do you think psychosis literacy would or wouldn't encourage you to seek help if you were experiencing symptoms of psychosis?

•Do you think psychosis literacy could make you better at recognising symptoms of psychosis among your family and friends?



Should young people have increased awareness about psychosis?

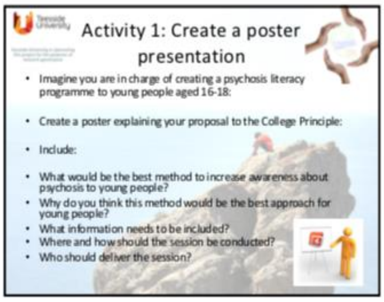
•Would 'psychosis literacy' take away any misconceptions about the illness and affect how people with a psychosis would be viewed?

•Would psychosis literacy make you feel more frightened or less frightened regarding psychosis?

•What do you think parents and teachers would think about implementing such awareness in schools and colleges?

•Do you think young people would want some form of psychosis literacy and why?

•What age do you think would be most appropriate for such awareness to be given?



Activity 1: Create a poster presentation

- Imagine you are in charge of creating a psychosis literacy programme to young people aged 16-18:
- Create a poster explaining your proposal to the College Principle:
- Include:
- What would be the best method to increase awareness about psychosis to young people?
- Why do you think this method would be the best approach for young people?
- What information needs to be included?
- Where and how should the session be conducted?
- Who should deliver the session?

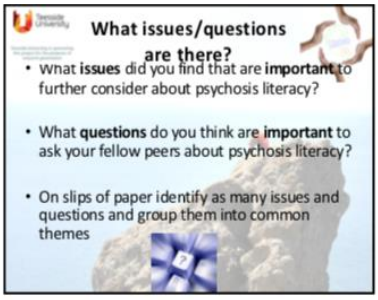
Feedback/presentation

What were your ideas?

Peer researcher training

Session 1: What is research for?

- What do you already know about research?
- Why is research important?



What issues/questions are there?

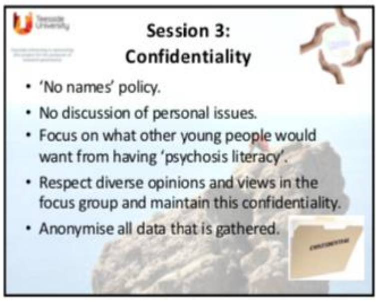
- What **issues** did you find that are **important** to further consider about psychosis literacy?
- What **questions** do you think are **important** to ask your fellow peers about psychosis literacy?
- On slips of paper identify as many issues and questions and group them into common themes

How can we engage young people in your research?

- How can we engage young people in the research focus groups?
- Develop activities you would find engaging

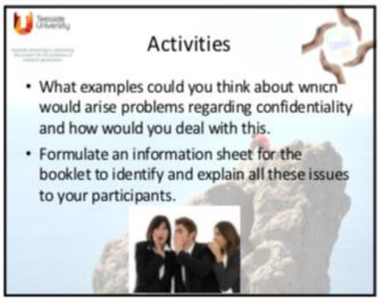
Session 2: Reasons for conducting your research.

- Create an **information booklet:**
- Why are you considering the topic of **'psychosis literacy'**?
- Explain your research **aims and objectives**.
- What is peer research and why are you using this method?
- What **benefits** and **potential risks** are there conducting the research?



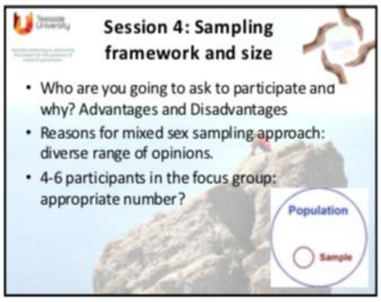
Session 3: Confidentiality

- 'No names' policy.
- No discussion of personal issues.
- Focus on what other young people would want from having 'psychosis literacy'.
- Respect diverse opinions and views in the focus group and maintain this confidentiality.
- Anonymise all data that is gathered.



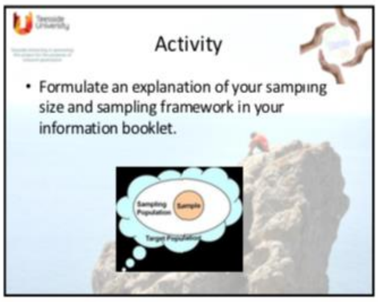
Activities

- What examples could you think about which would arise problems regarding confidentiality and how would you deal with this.
- Formulate an information sheet for the booklet to identify and explain all these issues to your participants.



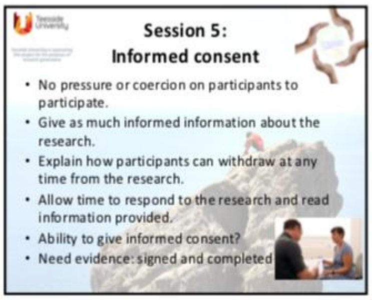
Session 4: Sampling framework and size

- Who are you going to ask to participate and why? Advantages and Disadvantages
- Reasons for mixed sex sampling approach: diverse range of opinions.
- 4-6 participants in the focus group: appropriate number?



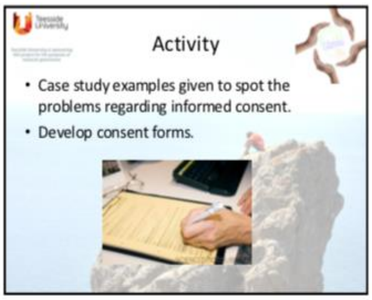
Activity

- Formulate an explanation of your sampling size and sampling framework in your information booklet.



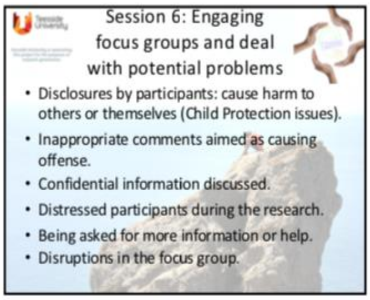
Session 5: Informed consent

- No pressure or coercion on participants to participate.
- Give as much informed information about the research.
- Explain how participants can withdraw at any time from the research.
- Allow time to respond to the research and read information provided.
- Ability to give informed consent?
- Need evidence: signed and completed



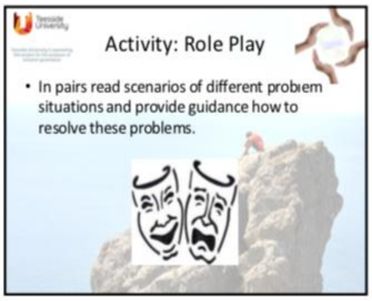
Activity

- Case study examples given to spot the problems regarding informed consent.
- Develop consent forms.



Session 6: Engaging focus groups and deal with potential problems

- Disclosures by participants: cause harm to others or themselves (Child Protection issues).
- Inappropriate comments aimed as causing offense.
- Confidential information discussed.
- Distressed participants during the research.
- Being asked for more information or help.
- Disruptions in the focus group.



Activity: Role Play

- In pairs read scenarios of different problem situations and provide guidance how to resolve these problems.

Appendix 6: Request for ethical approval, relevant letters/information and consent forms

Using young people’s views to help shape education to support mental health

Request for ethical approval

Andrew Ramtohul

UNIVERSITY OF TEESSIDE

CONFIDENTIAL

REQUEST FOR ETHICAL APPROVAL

Please return form with
Section A completed to:
The Secretary, Research
Ethics Committee
School of Health and Social Care

Section A: To be completed by the appropriate Project Supervisor or Director of Studies

1. School: Health and Social Care

2. Project Title:
Listen Up: Using young people's views to help shape education to support mental health

3a): Name, position and address of Project Supervisor/Director of Studies:
Professor Janet Shucksmith
Assistant Dean (Research)
School of Health & Social Care
Teesside University

3b): Name(s) and position of other Supervisor(s):
Dr Lisa Arai
Senior Lecturer in Research Methods
School of Health & Social Care
Teesside University

3c): Names of other collaborators on project:

4. Name(s) of Researcher(s)/Students working on this project:
Andrew Ramtohul

Please tick type of Researcher:

Taught Post graduate		*PG Research Student*	✓	*Staff - higher degree*		*Staff - other research*		*Final Yr Under-graduate Student*	

5. Expected duration of project from: **September 2012 to June 2013**

6. Aim(s) of Project:
1. To explore the existing knowledge of psychosis in a sample of young people (aged 16-18 years) using focus group methodology
2. To empower young people to explorepsychosis literacy with other young people of the same age using a participatory peer research methodology.

7. Briefly describe the design of the project:
Qualitative semi-structured focus groups will be carried out within a participatory peer research methodology.
The research will be divided into five phases:

Phase 1: Scoping and preparation phase (January 2011 to August 2012. Ethics not required)

Phase 2: Recruit PRs and focus group sessions (September 2012 to October 2012)

Phase 3: PR training (November 2012 to January 2013)

Phase 4: PRs conducting research (February 2013 to March 2013)

Phase 5: Analysis and dissemination of proposals from research

Please see Appendix 1 for a copy of the Research Protocol which provides full detail the design of the project.

8. Will the participants be: (please tick as appropriate)	*University of Teesside Students?*		*University of Teesside Staff?*	

Other: (Please specify):
PRs: North East Further Education College students studying Health and Social Care. Aged 16-18.
Participants: Chosen by PRs through social networks/friendships through snowballing sampling techniques, aged 16-18 from their locality.

9. How many participants will be involved?

It is difficult to give a definite number of participants at this stage since the programme of work for the project has not yet been finalised. I imagine from interest already expressed by students that 6-12 PRs will be recruited from the potential framework of 33 students studying Health and Social Care at a North East Further Education College in their 2nd Year. No more than 12 PRs will be recruited due to the intensity of training and supervision needed with one trained researcher. If more than 12 PRs want to participate, they will be chosen on a first come, first chosen basis. Those participants who are not chosen will be given the possibility of being involved in a future extended study if they wish. No less than 6 PRs would be needed to ensure that there is enough variety of different opinions and views involved in the research. If less than 6 PRs were recruited the sampling framework would have to be increased to Year 1 students or another Further Education College. Letters to Further Education colleges will be sent out in Phase 2 of the recruitment of PRs (see Appendix 6).

Each of the PRs recruited will be asked to recruit 2-3 young people aged 16-18 from mixed sex friendship groups to be involved in the focus group. Each focus group will have 2 PRs conducting the group with the participants they have recruited.

	Minimum of 3 Focus groups	**Maximum of 6 Focus groups**
Minimum number of participants (4 in each group)	12	24

Maximum number of participants (6 in each group)	18	36

Hence the range of participants that could be recruited could range from 12 to 36 young people.

10. State how participants will be selected:

Phase 2:

PRs will be selected from the framework of a potential of 33 students studying Health and Social Care at a North East Further Education College, which has given full permission for this research to be carried out at this establishment. A letter will be given to the course leaders of the college (see Appendix 6) outlining the nature of the research, which will also be given to other North East Further Education Colleges if participants are not recruited here. All students will be presented with full information about the research via a PowerPoint presentation (see Appendix 1) and a take away information pack (see Appendix 6) which will explain what expectations there are on being a PR. It will be emphasised that participation does not provide any favouritism in their course and that those who do not participate will be provided with the same amount of support in their course as those who do participate. Students will then be given a week to decide whether or not they want to participate, emphasising that their participation would be entirely voluntary. The students will inform the researcher if they want to participate or not by filling in a tear off slip to reduce the risk that students feel pressurised in the classroom to volunteer.

Once names of students have been expressed, their suitability to be part of the research will be decided by scrutiny of their consent form (that they have agreed that they would feel comfortable in discussing sensitive issues regarding psychosis).

Phase 4

PRs will work in pairs and will recruit participants through social networks/snowballing. PRs will then apply their research training by following ethical guidelines that they have developed themselves. This will involve gaining informed consent which will ask the young person to confirm that they have not and do not currently suffer from a mental health condition. Young people recruited will also be made aware of the sensitive issues that may be discussed and agree that they are comfortable in participating in this research, respecting each other's' opinions and views without aiming to be offensive. Emphasis will be placed on the need to maintain confidentiality and not to disclose any personal information during the focus groups. Consent forms must be signed agreeing to these expectations of participating in the research.

Two PRs will be involved for each focus group, in which each PR will choose 3 or 2 friends aged 16-18 to participate, with one participant being of the opposite sex. The rationale behind this is to ensure that there is a mixed sex sample to ensure that there is a variety of different opinions and to create an effective group dynamic for the focus group.

11. Has statistical/methodological advice been sought on the size and design of the project? YES

(If YES, please state name of adviser and qualifications)

Professor Janet Shucksmith, Teesside University

Professor KayTisdall, University of Edinburgh

***12. What procedure(s) will be carried out on the participants**? (Explain in terms appropriate to a layperson)*

Phase 2 and 3:
PRs
PRs will be involved in three research sessions. A topic guide has been provided in Appendix 2 and PowerPoint presentation that will be used is provided in Appendix 5. PRs will be involved in 6 sessions of training. A topic guide has been provided in Appendix 2.

Phase 4:
PR's participants
Participants will be engaged by PRs in similar focus groups to those conducted in the three research sessions in Phase 2. However the format for these will be developed by PRs during their training sessions in collaboration with the principle researcher. Principle researcher will be present and accessible in the college while the research is conducted by the PRs so that appropriate support can be provided if there are any potential problems that occur.

Principle researcher has attended training on 'Involving Children and Young People in Research and Consultation' by the Centre for Research on Families and Relationships based at the University of Edinburgh. Principle researcher has therefore gained the skills and competency to carry out relevant research procedures to engage young people in research.

13a): What potential risks to the interests of participants do you foresee?

1) I foresee no physical risks to participants; but discussion about psychosis could potentially be upsettingand distressing.

Control Measure: Ensure that measures are in place in the consent form agreeing that PRs and PR's participants are comfortable in discussing this topic and that they are aware and comfortable that sensitive issues may be discussed. To work alongside the student's personal tutor to ensure that any students whom the teacher is aware has had or still have mental health problems are excluded. The researcher and PRs are available to give support and to direct participants to relevant agencies if they want more information about the topic. Ensure that participants are made aware that they can withdraw from the research at any time.Researcher andPRsestablish ground rules of respecting each other's opinions and rule against any purposeful offensive comments being made.

2) There is potential for young people to disclose information about themselves or others that would breach confidentiality or involve Child Protection issues.

Control Measure: Young people will be warned not to discuss matters of a revealing personal nature or to talk about other individuals by name in a ground rule setting opening activity. Should young people raise any issues that in the view of the researcher seem likely to lead the young person into harm or danger, the researcher will report the matter to the teacher with responsibility for pastoral care. PRs will be trained regarding this issue, and will devise a handbook for participants which will outline guidance regarding this and will remind participants of this rule throughout the session.

3) There is potential that participants may self-diagnose themselves with a psychosis and therefore worry about their mental health unnecessary.

Control Measure: To ensure that participants are fully informed about experiences of having a psychosis and are not misinformed in anyway. If participants are worried, ensure that they have the chance to gain further information from the researcher, PRs and relevant agencies such as Young Minds.

4) Participants may become financially or socially disadvantaged by having to participate in the study.

Control Measure: To ensure that participants are asked when the timings and locations of the sessions are held at a time most convenient for the participants. This will include ensuring that the young people are not required to miss their mode of transport, for example, the free college bus. To ensure that refreshments are provided during lunch time and that the young people are not asked to miss any valuable lesson time. Ensure that the focus groups held are relaxed and comfortable within friendship groups.

5) PRs may feel compelled to volunteer to please others

Control Measure: Ensure PRs are aware that there will be no favouritism given towards those who participate. Ensure that students are given a week to think and make a decision about participating and do not have to contact the researcher directly, but via a self-return tear off slip indicating whether or not they want to participate. Principle researcher is not employed or a teacher of the college which the students are recruited from.

6) Young people who are recruited by the PRs may feel compelled to participate because they feel pressurised by their friends and do not want to let them down.

Control Measure: Ensure that the PRs are trained appropriately to ensure that voluntary informed consent is ensuredwithout any element of pressure to recruit participants.

7) Young people may feel bored or not interested in the research that is conducted and therefore not participate in the research.

Control Measure: Principle researcher has the relevant training on ‘Involving Children and Young People in Research and Consultation’ by the Centre for Research on Families and Relationships based at the University of Edinburgh to ensure that the research conducted is appropriate and interactive enough to engage young people in the research.

13b); What potential risks to the Researchers do you foresee?

1) There is potential risk that PRs might rely too much on the researcher to create material for their research and demand more incentives to conduct the research

Control Measure: Ensure in the ground rules set that expectations of the research are established and that the PRs understand what their role is and what the Researcher’s role will be to facilitate the project.

2) There is a potential that the amount of time dedicated to the research project could restrict the Researcher’s social, personal and work life.

Control Measure: Ensure that a strict timetabled schedule is set to enable the Researcher to satisfy all tasks that he needs to complete. To ensure that the researcher is adequately supervised during the research project work, receives support at work and is able to talk to someone if he feels that the pressure of work is too much.

3) Participants in the research may disclose sensitive issues that will require professional debriefing and support, including the possibility of directing participants to relevant agencies to provide further support and guidance.

   Control Measure: The principle researcher is a qualified Mental Health Nurse and a qualified teacher with experience in providing pastoral support to students as well as professional mental health support to young people. The principle researcher will be contactable throughout the project and will be able to direct the young people to relevant external and internal agencies if required.

14 a): Will informed consent be obtained from all participants? YES

(If written, attach a copy of the consent form and information sheet)

See Appendix 6

14b):If NO, why not? *(Provide rationale.)*

15: If there is doubt as to a subject's ability to give consent, what steps will be taken to ensure that the subject is willing to participate *(e.g. assistance of independent colleague/next of kin or other means.)*

There should be no question about the participant's ability to consent to take part in the research as all participants are aged 16-18.No parental consent is deemed necessary due to the age of participants and because the rationale of peer research methodology is about protecting the right of young people to 'participate' and express their opinions (Beazley et al., 2011). It has been argued that gaining parental consent may provide a barrier in achieving this right and also gives the impression that participants do not have the ability to consent by their own right. It is important in this research that participants feel that they are trusted to be able to decide to participate in the research by their own freewill, recognising their agency and citizenship (Tisdall, 2008). Peer researching can then reduce the power balance that often occurs between young people and the 'researcher' if the young people feel in control of the research without the need to have parental consent (Beazley et al., 2011).

If there is any doubt whether the PRs can give informed consent, then it will be determined by the researcher that the participant will not be able to participate in the research. PRs through their research training will work alongside the researcher to ensure that all participants that have been recruited by the PRs have the ability to give informed consent, and if not the participants will not be able to participate. This will be carried out by ensuring that all participants are competent, entirely free to volunteer to participate (no feeling of being pressurised) and are given at least a week to make their decision, with full information given about the research, and, finally, the PRs and the researcher through question and answer sessions will ensure that participants can paraphrase what the research is about and what their involvement will include.

16: What information will be given to subject(s)?: *(Attach copies of letters or information sheets to be given to participants.)*

All students studying Health & Social Care will be approached and given an invitation letter (see Appendix 6), information sheet (see Appendix 6) and will be presented with a PowerPoint presentation about the research (see Appendix 1). If students agree to take part in the research they will be asked to sign a consent form (see Appendix 6).

Once PRs have been selected they will undergo a series of 6 peer research sessions in which they will produce their own version of an invitation letter, information sheet and consent form.

17: Where will consent be recorded?

Signed informed consent will be obtained from all participants (see above)

18a): Will participants be informed of their right to withdraw? YES

18b): If not, why not? *(provide rationale)*

19: Does the project involve any other disciplines and/or Ethics Committees? NO
(If YES, please state which and what approval has already been obtained – attach documentation.)

20: Will payments to participants be made? NO
(If YES, state amount and whether payment is for out-of-pocket expenses, or a fee.)

21a): Will the project receive financial support from outside the University of Teesside?
NO

21b):If YES, specify the nature and source of the support:

21c) If YES, have any restrictions been imposed upon the conduct of the research?
NO

22: Will any restrictions be placed on the publication of results? NO
(If YES, please state the nature of the restrictions)

23: Are there any other points you wish to make in justification of the proposed study?
In justification of the above study I emphasise the importance of promoting peer research participatory methods to comply with Article 12 of the Convention on the Rights of Children (CRC) that young people should have the right to form his or her views to express those views freely in matters affecting them. The rhetoric of participation should be avoided in adult-organised research; instead young people should take an active role in research (Beazley et al. 2011).

Peer research methodology also complies with Article 13 of the CRC, aimed at creating freedom of expression, ensuring that research questions are posed so that children feel comfortable and understand what is being asked. The research needs to be children friendly, and methods cannot be developed, used or evaluated independently of children. Children need to be partners in the research, sharing control of methods used, the questions asked, the way questions are asked, the analysis and dissemination of results (Beazley et al. 2011).

Having PRs will therefore enable young people to not feel disempowered by the authority of the adult ‘researchers’, which can be an intimidating process. Instead the young people will be discussing issues amongst their friends in an approach that is much more informal and friendly. Instead of answering questions that the researcher expects to hear, there is more likelihood hopefully that the participants will not feel intimidated when answering questions more truthfully and more in-depth.

The variety of participatory methods used during the research project will be utilised to make young people feel in control of the research and enable them to express themselves, and become valuable prompts in the process of asking semi-structured questions. Methods used will ensure that the children are left to feel positive about themselves, their lives and their participation in the research, despite the sensitivity of the topic.

The researcher is an experienced Mental Health Nurse and Lecturer, and has a good understanding of the capacity of the potential PRs from his previous employment. Therefore participants should feel comfortable during the pilot research sessions and the peer research training sessions.

Due to the sensitivity of the topic it will be ensured that the research will be conducted in the safety of the college where the researcher will be easily contactable if any problems arise during the focus groups that are conducted by the PRs.

***24*: I have read the University’s guidelines on ethics related to research, and to the best of my knowledge and ability confirm that the ethical considerations overleaf have been assessed. I am aware of and understand University procedures on Research Ethics and Health & Safety. I understand that the ethical propriety of this project may be monitored by the School’s Research Ethics Sub-Committee.**

(Please complete the following as appropriate) *Please Tick*

▪ **I have appropriate experience of the general research area.**	✓
▪ **I confirm that I have Research Ethics Training required by my School.**	✓
▪ **I confirm that as Supervisor that I will monitor progress of the project.**	✓
• **I confirm that the project complies with the Code of Practice of the following Professional Body:**	✓

25:

Signature of Staff Researcher: ____________________ *Date:* _________

***OR**: Signature of*

Project Supervisor/Director of Studies _______________ Date: _________

References

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Protocol:
Listen Up: Using young people's views to help shape education to support mental health

Background

'Psychosis' is often incorrectly used as a synonym for 'schizophrenia'. In fact psychosis is more correctly defined as encompassing a range of symptoms such as 'hallucinations, delusions, and/or gross disorganisation of thought or behaviour' (Tsuang et al. 2000: 1041). The term 'psychosis' is therefore an umbrella term to describe symptoms that can occur when people suffer from a range of disorders such as schizophrenia, bipolar disorder, schizoaffective disorder, dementia, some personality disorders, Parkinson's disease, drug/alcohol abuse, the side effects of some types of medication, severe stress or anxiety, severe depression or sleep deprivation.

Some of these conditions are notoriously difficult to diagnose however. In 2002, NICE calculated that 4 in every 1000 children aged between 5 and 18 suffered from 'schizophrenia' (NICE, 2011: 2), but this statistic is likely to exclude hidden numbers of undiagnosed, misdiagnosed and other psychotic illnesses, indicating that the true incidence of psychosis in young people may be a great deal higher. Poorly understood by lay people and difficult to diagnose, psychosis is thus a significant problem for young people. When it is recognised and treated early, young people suffering from these symptoms can find their condition much improved. When it is not recognised and the symptoms ignored, young people's condition may grow worse and they can become stigmatised very quickly for their odd behaviour. Psychosis literacy has therefore been argued as an important educational tool in the fight to advance understanding and reverse negative stereotypes. The concept of psychosis literacy exists 'between the worlds of mental illness intervention (psychiatry), mental health problem prevention (public health) and mental health promotion (health promotion and health education)' (Nind & Weare, 2009: 2). Little joined-up thinking between these areas has meant the neglect of coherent research in this area. Psychosis literacy aims to increase knowledge and understanding of 'psychosis' – focusing on the facts and taking away the myths/stigma of the condition.

80% of adolescents are deterred from seeking help with psychiatric disorders (WHO, 2005) by fear of stigma and negative stereotyping. Better psychosis literacy could enable earlier recognition of signs and symptoms in young people themselves and in others close to them, leading to earlier treatment and quicker recovery. As long ago as 2002 the Newcastle (UK) Early Psychosis Declaration tried to establish the principle that 'all 15-year-olds are equipped by mainstream education to understand and deal with psychosis' (Bertolote & McGorry, 2005: 116). Despite strategic calls for action, there has been little or no movement in schools, however, towards trying to increase psychosis awareness. Focus has instead been directed towards *genera*l mental health wellbeing, and tackling issues such as bullying, alcohol, drugs, anxiety and depression. A number of educational programmes have been designed to improve early detection of psychosis and reduce stigma. For instance, Schulzeet al. (2003) *"Crazy? So what! It's normal to be different"* programme from Germany encouraged 14-18 young people to meet a young person with schizophrenia and the UK Charity Rethink developed *'The Mental Health Awareness in Action programme'which*showed short video about people living with schizophrenia within a Personal, Social and Health Education (PSHE) curriculum for Year 10 students. It is unclear, however, to what extent such educational interventions are based on sound evidence from research. Couture & Penn (2003) and Economou, Stefanis & Papadimitriou (2009) found that 'contact' with someone with a mental health illness is the most effective strategy to date. However such an intervention is difficult to implement in an educational context and a more effective form of education is needed. Sakellari, Leino-Kilpi & Kalokerinou-Anagnostopoulou (2011) undertook a literature review of effective educational interventions in counteracting stigma and discrimination in adolescents. Results of the review illustrate that educational interventions have a positive impact on adolescents' knowledge and attitudes towards mental illness and lead to a decrease in social distance scores. The lack of research on the topic and heterogeneity in study methods however make clear conclusions difficult.

The acceptability of implementing psychosis literacy in educational settings has thus been largely unexplored. In part, the effectiveness of psychosis literacy will be determined on the value and acceptability that young people perceive and place on this issue (Harrison et al., 1992: 107). It is also clear that relatively little of the literature has been undertaken from young people's own perspective and that this is now conceived of as a major omission in designing interventions (Philip et al., 2009). Young people have still not had a chance to become fully involved in discussing their perspective on psychosis and how psychosis literacy could be implemented. Understanding the perspective of young people will improve our knowledge about how to improve promotion, prevention, detection and treatment by diminishing the stigma associated with psychosis and promoting help-seeking behaviour (Collins & Holmshaw, 2008: 91). The use of medical terminology within an educational context, for instance, can pathologise a range of normal behaviours (Gott, 2003: 10). It is therefore important to explore what young people think about the concept of psychosis literacy.

Aims of this project

1) To explore the existing knowledge of psychosis in a sample of young people (aged 16-18 years) using focus group methodology
2) To empower young people to explore psychosis literacy with other young people of the same age using a participatory peer research methodology.

Study design and methods

The research study to be undertaken will be qualitative, based on conducting semi-structured focus groups within a participatory peer research methodology. The underlying rationale for this method is based on Article 12 of the Convention on the Rights of Children, which states the entitlement of children and young people to have the right to 'participate' and express their opinions (Beazley et al., 2011). Research needs to tell us what young people mean, not what adults *think* they mean. Instead young people need to be trusted to be able to make decisions; research needs to recognise their agency and citizenship (Tisdall, 2008). Children need to feel in control of the research to enable them to express themselves (Beazley, 2011). Peer researching can then reduce the power balance that often occurs between young people and the 'researcher', which can have a significant impact on the accuracy of results, given that participants tend to give responses that they think the researcher wants to hear. Lanyon et al. (2004)demonstrates the value of PRs giving advice about the appropriateness of language used in the research, which is essential when talking about a complex and confusing concept like 'psychosis'. Lanyon et al. (2004) also illustrates the value of PRs in helping develop the most appropriate participatory methods to engage young people in informal discussions; giving advice on the use of different methods such as games, structured interviews, semi-structured interviews, individual interviews and large focus groups. Hence, it is expected that in this research, PRs will prove valuable in developing the most appropriate method of exploring psychosis literacy (and the acceptability of educational interventions on the topic) with other young people.

The work will be undertaken in five phases:

Phase 1: Scoping and preparation phase (January 2011 to August 2012) (ethical permission is not required for this part of the study)

A substantial body of literature on this topic has already been accumulated, but will continue to be collected and consulted with further review of literature in peer reviewed journals. The study will be subject to full scrutiny by the School of Health and Social Care Research Ethics and Governance Committee prior to fieldwork being carried out and part of the work of this period is the preparation of the ethics paperwork.

Phase 2: Recruit PRs and pilot focus group sessions (September 2012 to October 2012)(ethical permission is being requested for stages 2-5 of the study)

Recruitment of sample

The researcher previously worked as a Lecturer in Health and Social Care and during informal discussions a number of young people expressed interest in the idea of working on this project as PRs. Participating in this way would enable the students to satisfy the requirements of their research module in Health and Social Care and would also benefit student's personal statements/CVs.

It is proposed that at the start of academic year 2012-2013, all thirty-two Year 2 Level 3 students (aged 16-18 years) studying BTEC National Extended Diploma in Health and Social Care would be given further explanation of the research and the possibilities of becoming a PR. This information will be outlined by the researcher in a PowerPoint presentation with slide notes provided (see Appendix 1) and an information pack (see Appendix 6). Students will then be given a week to decide whether or not they want to participate, emphasising that their participation would be entirely voluntary. It will be emphasised in the presentation that participation does not provide any favouritism in their course and that those who do not participate will be provided with the same amount of support in their course as those who do participate. The students will be asked to state whether or not they want to participate on a self-return tear off slip to reduce the risk that students feel pressurised in the classroom to volunteer.

Those interested in taking part will be asked to fill and sign an informed consent form(see Appendix 6) which will explain that the topic of 'psychosis' will be explored and that there may be sensitive issues discussed. The participants therefore agree that they would feel comfortable being involved in such discussions. It will be emphasised that if they feel that they would be uncomfortable discussing this issue that they should not be involved. The young people who consent to the research will be invited to contact the researcher to discuss the research, should they wish to have further information.

It will be explained that only 12 students are needed to become PRs in this research, and if more than 12 students are interested in participating the research the students will be chosen on a first come, first selected basis. Those students who were not selected to participate will be sent a letter explaining that they have not been selected but that there details will be kept if they wish to be possibly contacted in a future related research (see Appendix 6).

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Gaining informed consent

Confirmed PRs (c.12 students) will be sent a letter confirming their participation and inviting them to attend their first meeting (see Appendix 6). Groups will consist of all young people recruited and will be held in a classroom within the college and will be facilitated by the researcher, Andrew Ramtohul. Another researcher will also be in attendance to ensure smooth running of the sessions and to enable note taking. Refreshments will be provided by the researcher.

At the start of the first session the young people will once again have the whole process explained to them verbally and will then be asked to complete and sign an informed consent form before they can participate (see Appendix 6). Part of this explanation will involve establishing ground rules for confidentiality within the focus group sessions and afterwards. Young people will be told that their contribution is required in terms of general ideas and opinions and that they will not be encouraged to explore or explain personal instances of mental health problems or recount instances amongst other people with whom they have been in contact. All information provided will be anonymised in the research. It will be explained to them, that they may cease participation in the research at any point without jeopardy to themselves, but that their contribution to the group – once given – cannot be extracted from the record.

It is possible that some participants might try to discuss personal issues, such as a family member suffering from psychosis. If this occurs participants will be reminded not to disclose personal information and not to mention names. If young people disclose information which could indicate risk of harm to themselves or others, it would have to be explained again (this information will already have been within the informed consent protocol) that this information would have to be passed on to the college Child Protection Team. If a participant became upset regarding issues discussed during the research, the assistant will help the student to leave the setting and will give temporary support. After the session the researcher (a trained teacher and Mental Health Nurse) will talk further with the student and direct him/her to relevant agencies that can support them. The researcher will always carry with him further information for all interested students and details of other support agencies within the college and beyond.

Parental consent is not required due to participants being aged 16-18 and therefore will be deemed as being able to give informed consent. Due to the rationale of peer research being based on Article 12 of the Convention on the Rights of Children, which states that children and young people have the right to 'participate' and express their opinions (Beazley et al., 2011) it has been argued parental consent would give the impression that the participants do not have the ability to consent on their own. It is important instead that the participants feel that they are trusted to be able to make decisions and participate in the research by their own freewill. The research needs to recognise participants' agency and citizenship without the need for parental consent (Tisdall, 2008). Peer researching can then reduce the power balance that often occurs between young people and the 'researcher' if the young people feel in control of the research (Beazley, 2011).

Focus group sessions

PRs will be involved in three one hour sessions over a period of 3 weeks (one every week).

Session 1: Explore young people's existing knowledge of psychosis.
Session 2: To explore with the group their views on developing a psychosis literacy session for young people utilising different media methods.
Session 3: To explore with the group their views and opinions regarding formulating appropriate psychosis literacy programme for schools and colleges in light of their experiences.

Sessions will involve participatory methods using video clips, ranking post-it notes, vignettes, thought-showers, PowerPoint slides and various leaflets/information sheets.

Recording and storing data
Focus groups will be audio-recorded with permission of all participants. If any individual participant refuses to be audio-recorded then the researcher will conduct note-taking for the group instead. Data will subsequently be transcribed and stored securely on a password encrypted machine at the researcher's own home, to which only the researcher has access. These transcripts will be entered into NVivo in order to manage the data. At the point of transcription the researcher will anonymise the participants, ascribing them pseudonyms of their own choosing. The list connecting real names with pseudonyms will be held separately and securely by the researcher by being stored on the researcher's password protected Teesside University server (U-Drive) not on a home computer.

The researcher will use Thematic Content Analysis to make sense of the data and extract emergent overarching themes and subthemes. Once this has been conducted the researcher will work with the PRs using member checking to ensure that the correct interpretation of the data was established. The researcher will then work with PRs in formulating an appropriate method to disseminate results to the PRs.

Phase 3: PR training (November 2012 to January 2013)

The aim of this part of the research is to train a selected group of young people how to become secure and ethical researchers themselves so that they can conduct a mini study on this topic amongst their contemporaries.

First session: The aim will be to review the findings that have emerged from the pilot focus group sessions. From the review, to consider how the research could be improved and what issues seem to be relevant to discuss in their research focus groups. What issues seem to be relevant to the young people and how could the focus groups be made more user-friendly for adolescents?

Second session: Reasons for conducting their research.

PRs start to create an information booklet to give to their participants, explaining the research aims and objectives. Why are they conducting peer research? Why are they considering the topic of psychosis literacy? What benefits and potential risks are there conducting the research?

Third session: Explanation of confidentiality issues.

Explain the importance of a 'No names' policy and not to discuss personal issues in the focus group, but focus on what other young people would want from having psychosis literacy. To respect diverse opinions and views in the focus group and maintain this confidentiality. To anonymise all data that is gathered. For the PRs to formulate an invitation letter and information sheet for the booklet to identify and explain all these issues to their participants.

Fourth session:
Discuss appropriate sampling framework and size, and for students to commence scoping.

Explain who the PRs are going to approach to ask if they would like to participate in the research and reasons why they were chosen? The reasons why a mixed sex sampling approach would be appropriate (aim to gain a diverse range of opinions). The reason why 4-6 participants in the focus group would be an appropriate number, disadvantages of a large focus group. For students to then formulate an explanation of their sampling size and framework in their information booklet.

Fifth session: Discuss informed consent and develop consent forms.

Explain the importance of not placing any pressure or coercion on participants to participate and how this can be achieved. Give as much informed information about the research. Explain how participants can withdraw at any time from the research and allow time for participants to respond to the research and read information provided. Assess whether participants have the ability to give informed consent, and that they are comfortable to participate. PR to develop consent forms and ensure that these are signed and completed before participation begins.

Sixth session: Discuss how to engage a focus group and deal with potential problems with participants.

For participants to engage in role play scenarios and how to appropriately deal with each situation:

7) Disclosures by participants which would either cause harm to others or themselves. How to breach confidentiality and deal with Child Protection issues.
8) Participants stating inappropriate comments which are deemed as aimed as causing offense.
9) Participants talking about confidential information about identifiable others and themselves.
10) Participants who become distressed during the research.
11) Participants who ask for more information or help that they cannot provide.
12) Dealing with participants who may cause disruption in the focus group.

Phase 4: PRs conducting research (February 2013 to March 2013)

PRs will work in pairs and will recruit participants through social networks/snowballing. PRs will then apply their research training by following ethical guidelines that they have developed themselves. This will involve gaining informed consent and the young people recruited will be made aware of the sensitive issues that may be discussed and agree that they are comfortable in participating in this research, respecting each other's' opinions and views without aiming to be offensive. Emphasis will be placed on the need to maintain confidentiality and not to disclose any personal information during the focus groups. Consent forms must be signed agreeing to these expectations of participating in the research. PRs will be trained thoroughly regarding these issues in stage 3 to ensure that ethical safeguards are met and maintained. The researcher, Andrew Ramtohul, will oversee that the PRs have conducted the research appropriately abiding by the ethical guidelines that they developed during their training.

Focus groups will aim to comprise of mixed sex friendship groups, no larger than 6 participants. A minimum of 2 to a maximum of 4 focus groups will be conducted by each pair of PRs. Each focus group will have two PRs: one taking the lead asking questions and the other facilitating resources and taking notes during the meeting. Participatory material developed by the PRs will be given to guide participants through a series of semi structured questions. Follow up and support information will be available to young people on request, and the researcher's name will be given to all participants as a first port of call should further advice and information be required.

Focus groups will be audio-recorded with permission of all participants. If participants refuse to be audio-recorded then one of the PRs will concentrate on taking notes. Data then will be transcribed and stored securely with the consent of participants. These transcripts will be entered into NVivo in order to manage the data.

Phase 5: Analysis and dissemination of proposals from research

The researcher Andrew Ramtohul will use Thematic Content Analysis to make sense of the data and extract emergent overarching and subthemes. Once this has been conducted the researcher will work with the PRs using member checking to ensure that the correct interpretation of the data was established. Involvement in the analysis will increase ownership in the research for the young people and bring new meanings in the interpretation (Davis, 2008). The researcher will then work with PRs in formulating an appropriate method to disseminate proposals from the research, in which all data provided will be anonymised to protect the confidentiality of those participating.

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Andrew Ramtohul
Northumbria University
Coach Lane
Benton
Newcastle upon Tyne
NE7 7XA

DATE

Dear [Insert student's name],

Listen Up: Using young people's views to help shape education to support mental health

I would like to invite you to take part in a study to explore young people's knowledge, opinions and views about the need for 'psychosis literacy' for young people. 'Psychosis literacy' is about increasing awareness, knowledge and understanding of the nature of psychosis, a Mental Health disorder which includes the diagnosis of schizophrenia. Awareness and knowledge about psychosis is an area of health promotion that has been significantly under-explored.

Your involvement would involve taking part in three pilot focus group sessions to talk about 'Psychosis literacy'. The discussion will take place during the college days of ************. Then I would like to invite you to attend six 'Peer Research Training Sessions' which are intended to prepare you with the skills needed to become a 'PR'. These training sessions will take place during the college days of ************. Once you have the necessary research skills you will be asked to recruit two or three participants (mixed sex and aged 16-18) and conduct a focus group session with another fellow student.

More information about what the study will involve can be found in the enclosed information leaflet.

If you agree to take part in the initial focus groups, the training and working with peers, please would you complete the tear off slip on the information sheet and return it in the envelope provided.

If you require more information about this study then please contact Andrew Ramtohul on 01642 ****** or email him on a.ramtohul@tees.ac.uk

Yours faithfully,

Andrew Ramtohul
PhD Student
Lecturer Mental Health Nursing
MA, PGCE, BSc, RNMH, BA

UNI LOGO HERE

Listen Up: Using young people’s views to help shape education to support mental health

Information for students

Who is conducting this research?

This project is being carried out by Teesside University PhD student Andrew Ramtohul under the supervision of Professor Janet Shucksmith.

Why do I want to do this work?

- People’s negative and inaccurate attitudes towards people suffering from a ‘psychosis’ needs to be changed to improve lives and prevent stigma

- I want to improve mental health education to enable young people to gain accurate knowledge and awareness about ‘psychosis’

- I want to find out about young people’s own views and increase young people’s voice

- I believe young people have a right to influence the future of their mental health education and play a significant part in reducing stigma in mental health

Why have I been chosen to participate?

You have been chosen because you are aged 16-18, you are learning research skills in Health & Social care and this project will give you the opportunity to expand on these skills with the opportunity to change current practice for young people’s Mental Health promotion. A maximum of 12 students will be selected on a first come, first chosen basis. If there are more than 12 students who want to participate they may be able to be involved in a possible future extension of the project.

Do I have to participate?

You don’t have to take part in this study if you don’t want to. Non-participation will not affect any aspect of your college work and participation in the project will not result in any form of favouritism. If you do decide to take part the researcher will ask you to sign a form to show you agreed to take part. To qualify for participation you must sign to agree that you have not and do not have a mental health problem, that you fully understand and are comfortable with discussing sensitive topics related to psychosis and that you agree not to discuss personal issues in the focus group relating to yourself or other identifiable others.

What will I have to do if I take part?

You will be asked to attend three one hour focus group sessionsduring the college days of ************; refreshments will be provided:

Session 1: Explore young people’s existing knowledge of psychosis.

Session 2: To explore with the group their views on developing a psychosis literacy session for young people utilising different media methods.

Session 3: To explore with the group their views and opinions regarding formulating appropriate psychosis literacy programme for schools and colleges in light of their experiences.

Then you will be invited to attend six one hour ‘Peer Research Training Sessions’ to prepare you with the skills needed to become a ‘PR’ yourself during the college days of ************:

First session: Reviewfindings from the pilot focus group sessions

Second session: Reasons for conducting their research
Third session: Explanation of confidentiality issues
Fourth session: Discuss sampling framework and size: commence scoping
Fifth session: Discuss informed consent and develop consent forms
Sixth session: Discuss focus group strategies and dealing with potential problems

Once you have the necessary research skills you will be asked to work with a fellow PR to recruit two or three participants from friendship groups (mixed sex and aged 16-18) and conduct three one hour focus group sessions.

What happens to the information that is collected?

The recording of your conversation in the phase 2 focus group sessions will be written up and used to formpart ofthe report together with the main discussions held by your PRFGS in phase 4. No personal details (name, address etc) will be disclosed in the reports. I will however use quotations of what you have said to illustrate points make in the report. I would normally be able to assure you of anonymity. However, as you know, you are the only students working on this project so anyone reading the reports that know who you are may be able to identify you. Please bear this in mind when making a decision about taking part in the evaluation. Any information you give us will be treated confidentially. This means that I will only tell people who have the right to know. The information you give us will only be used for research. So that I can be totally accurate about what is said in the groups I would like (with your permission) to tape record the sessions. These tapes will then be written up onto paper so that I can analyse them. Only members of the research team will listen to these recordings. The recordings of focus group sessions will be held securely at Teesside University in accord with the Data Protection Act (1998). All data will be anonymised and held for a minimum of 5 years and may be used for future study but only in research projects that have received ethical approval from an appropriate committee.

Can I choose to withdraw from the project?

You can leave the focus group at any time during the group without giving reason, however due to the interactive nature of the data collected it is not possible for you to withdraw any statements made prior to that point.

What happens next?

I hope that if you decide to participate in this research project that it will provide you with a valuable experience which will build your confidence, interpersonal skills and researching skills. You will obtain a Certificate at the end of the project in recognition of the time you have spent on the project.

Thank you for taking the time to read this information sheet. If you have any questions or concerns regarding the project please do not hesitate to contact the researcher Andrew Ramtohul on 01642****** or email him at a.ramtohul@tees.ac.uk.

Please fill in the tear slip below indicating whether or not you intend to participate. If you agree to take part please complete the tear off slip and put them in the pre-addressed envelope for me to collect via your college tutor.

✂

………

My name is ....and I have been given all the relevant information about the research project “Listen Up: Using young people’s views to help shape education to support mental health”.

I understand the nature of the research and have decided that I **would like/would not want** (delete as appropriate) to participate in the Research Project.

If you wish to participate please supply your address, telephone number or email, and indicate your preferred mode and time (for telephone) of contact

Preferred mode
Please tick relevant box

Address:…………………………………………………................ ☐
…………………………………………………………………………..
Telephone:………………………………………………………….Time: ☐
E-mail:………………………………………………………………. ☐

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Listen Up: Using young people’s views to help shape education to support mental health

Consent Form

Please take the time to read the statements below. If you are happy to take part in the study please **initial each box**, **fill in the bottom of the sheet and return to the researcher.**

I confirm that the researcher has given me background information about the purpose of the study and that I have read and understood the information sheet dated **** and have had the opportunity to ask questions ☐

I understand that this research will involve discussing potentially sensitive issues about psychosis and I am comfortable in discussing these issues ☐

I understand that during research project all participants need to respect other people’s points of view but understand that it is not acceptable to be intentionally offensive during the research project ☐

I understand that my participation in the study is on a voluntary basis and that I have the right to withdraw at any time before [insert date] without having to give a reason. I understand that due to the interactive nature of the data collected, it is not possible to withdraw any statements made prior to that point. ☐

I understand that our conversations will be audio recorded, and that all interview tapes will be transcribed verbatim, checked for accuracy and subsequently destroyed after the date for withdrawal from the study. ☐

I understand that any information I give in this study will remain anonymous and confidential, and that no personal information will be used which may identify me in the final report. I understand that because I am one of few students to participate in this study that people that know me may speculate about the source of any quotes used in publications. I understand that no personal information or any information about other identifiable others should be discussed in the focus groups. ☐

I understand that the data obtained (transcripts) will be held securely at the University of Teesside, in accord with the Data Protection Act (1998). Only those directly involved in this evaluation will hear and see these. All data will be anonymised and held for a minimum of 20 years and may be used for future study (what is called secondary analysis) but only in research projects that have received ethical approval from an appropriate committee. ☐

I am aged 16-18 and have the capacity to give my consent in participating in this research. I have been given enough time (one week) to understand both the verbal and written information about the research, with the opportunity to discuss my involvement with my family/carers/friends. ☐

I have read each of the above statements and give my consent to take part in the study. ☐

Participant:

Name …………………….......Signature …………………Date …................

Researcher:

Name …………………….. ....Signature ………………….Date …................

Andrew Ramtohul
Northumbria University
Coach Lane Campus
Coach Lane
Benton
Newcastle upon Tyne
NE7 7XA

DATE

Dear [Insert Course Tutor's Name],

I am currently a Lecturer in Mental Health Nursing at Northumbria University and a part-time PhD student at Teesside University under the supervision of Professor Janet Shucksmith. I am writing to you regarding the prospect of being given permission to ask your Health & Social Care students, aged 16-18, whether or not they would like to participate in a PhD research project regarding Mental Health Education. The title of the project is **"Listen Up: Using young people's views to help shape education to support mental health"**, which has been approved by the Teesside University School of Health and Social Care Research Ethics and Governance Committee.

The form of research methodology chosen for this PhD project is called "Participatory Peer researching". This method has been chosen to comply with Article 12 of the Convention on the Rights of Children (CRC) to ensure that young people have the right to form and express their views freely in matters affecting them. Giving young people the opportunity to have an active role in research is an important step in achieving this aim, with the opportunity to influence the future of mental health education.

Participatory Peer research methodology also complies with Article 13 of the CRC, aimed at creating freedom of expression, by ensuring that young people feel comfortable in the research by allowing young people to become partners in the research. It is important for young people not to feel disempowered by the authority of adult ‘researchers’. Instead young people will be engaged in a variety of participatory methods, discussing issues amongst their friends in an approach that is much more informal and friendly. It is the aim that young people will not feel intimidated and will not be answering questions that the researcher expects to hear, but will answer questions more truthfully and more in depth.

Students who agree to take part will be asked to participate in three one-hour focus group sessions to discuss and be involved in various activities about mental health awareness and then six one-hour ‘peer research’ training sessions, where students will be professionally trained as ‘PRs’, including training regarding research ethics. It is expected that these one hour sessions will occur once every week, and will take place over a period between November 2012 to February 2013.Once it is felt that students are trained and competent they will conduct their research in pairs under my supervision from March 2013 to April 2013.

The research focus groups and peer research training sessions will all be organised during lunch breaks or during any free periods that the students think would be appropriate, including evenings. Refreshments will be provided and there will be no infringement on college lesson times.

It is hoped that initially about 12 students will be interested in being involved in this project. Students would benefit from experiencing an opportunity to be involved in a PhD research project and gain research skills as a PR (certificate provided) which would be transferable skills during their present and future studies.

If you feel that such a project would be suitable for your students, please do not hesitate to contact me to arrange a further discussion of the project at your college.

Yours sincerely

Andrew Ramtohul
MA, PGCE, BSc, RNMH, BA

Andrew Ramtohul
Northumbria University
Coach Lane
Benton
Newcastle upon Tyne
NE7 7XA

DATE

Dear [Insert student’s name],

Listen Up: Using young people’s views to help shape education to support mental health

Thank you for expressing your interest in the above research project and for completing your consent form. Our first session will take place during the college day of ************at ************ hours in room ************. Refreshments will be provided, so if you have any specialised dietary requirements please let me know prior to our first meeting.

If the date or time of the meeting stated above is inconvenient for you please let me know prior to our meeting so that an alternative date and time can be made as your participation is valuable.

If you have any more enquires about the research project please do not hesitate to contact me on 01642 ****** or email a.ramtohul@tees.ac.uk

Yours faithfully,

Andrew Ramtohul
PhD Student
Lecturer Mental Health Nursing
MA, PGCE, BSc, RNMH, BA

Andrew Ramtohul
Northumbria University
Coach Lane
Benton
Newcastle upon Tyne
NE7 7XA

DATE

Dear [Insert student’s name],

Listen Up: Using young people’s views to help shape education to support mental health

Thank you for expressing your interest in the above research project and for completing your consent form.

Unfortunately due to high demand in participation, you have not been selected to participate in the current research project.

However if you are happy for us to keep your details there may be the possibly for you to be contacted in a future related research depending on the outcomes of the current research project. If you are happy for us to keep your details or if you have any more enquires about the research project please do not hesitate to contact me on 01642 ****** or email a.ramtohul@tees.ac.uk

Yours faithfully,

Andrew Ramtohul
PhD Student
Lecturer Mental Health Nursing
MA, PGCE, BSc, RNMH, BA

Appendix 7: Ethics approval letter

Teesside University
Middlesbrough Tees Valley
TS1 3BA UK
www.tees.ac.uk

Teesside
University

PRIVATE AND CONFIDENTIAL

Direct Line: 01642 384124

5th October 2012

Janet Shucksmith
School of Health & Social Care
Teesside University

Dear Janet

Study No 144/12 - Listen Up: Using young people's views to help shape education to support mental health. Researcher: Andrew Ramtohul. Supervisor: Janet Shucksmith.

Decision: Approved

Thank you for submitting an amended application pack. I am pleased to confirm that the comments raised by the School of Health & Social Care Research Governance and Ethics Committee have been addressed in your amended application pack and your study has been approved through Chair's Action. Your study may proceed as it was described in your approved application pack.

Please note:

Where applicable, your study may only proceed when you have also received written approval from any other ethical committee (e.g. NRES) and operational / management structures relevant (e.g. Local NHS R&D). A copy of this approval letter **must** be attached to applications to any other ethical committee. If applicable please forward to me a copy of the approval letter from NRES before proceeding with the study.

In all cases, should you wish to make any substantial amendment to the protocol detailed, or supporting documentation included, in your approved application pack (other than those required as urgent safety measures) you must obtain written approval for those, from myself and all other relevant bodies, prior to implementing any amendment. Details of any changes made as urgent safety measures must be provided in writing to myself and all other relevant bodies as soon as possible after the relevant event; the study should not continue until written approval for those changes has been obtained from myself and all other relevant bodies.

On behalf of the School of Health & Social Care Research Governance and Ethics Committee please accept my best wishes for success in completing your study.

Yours sincerely

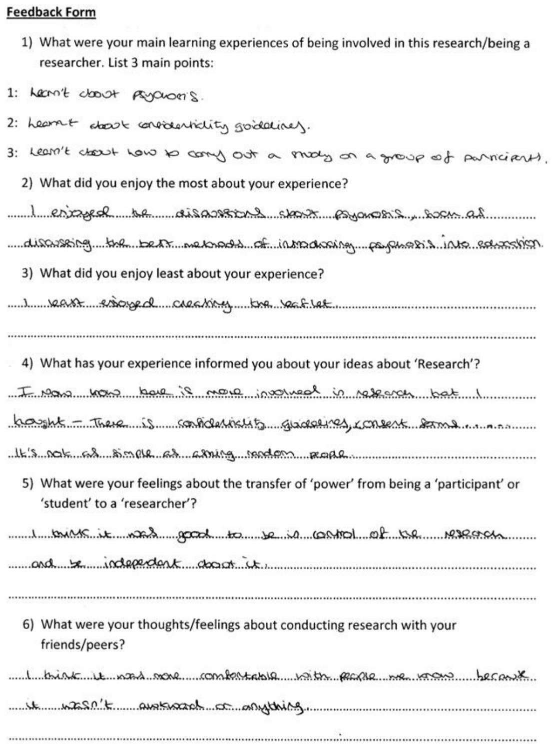
Dr. Alasdair MacSween
Chair
Research Governance and Ethics Committee
School of Health & Social Care

VAT REG NO. GB 686 4809 81

POSITIVE ABOUT DISABLED PEOPLE

INVESTOR IN PEOPLE

Appendix 8: Feedback forms completed by PRs.



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: learn't about psychosis.

2: learnt about confidentiality guidelines.

3: learn't about how to carry out a study on a group of participants.

2) What did you enjoy the most about your experience?

I enjoyed the discussions about psychosis, such as discussing the best methods of introducing psychosis into education.

3) What did you enjoy least about your experience?

I least enjoyed creating the leaflet.

4) What has your experience informed you about your ideas about 'Research'?

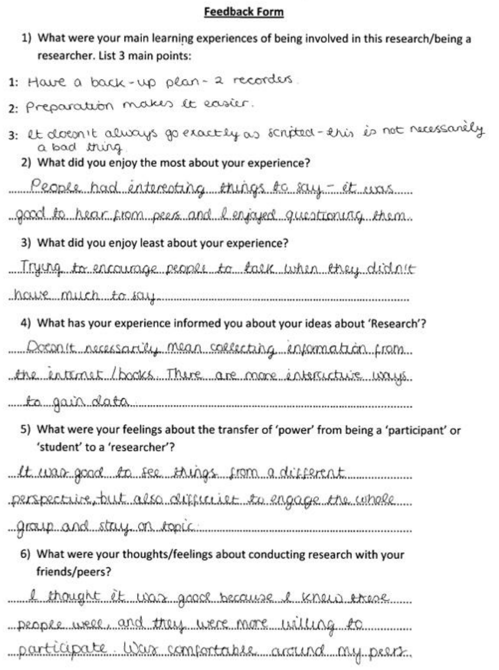
I now know there is more involved in research than I thought – There is confidentiality guidelines, consent forms..... It's not as simple as asking random people.

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

I think it was good to be in control of the research and be independent about it.

6) What were your thoughts/feelings about conducting research with your friends/peers?

I think it was more comfortable with people we know because it wasn't awkward or anything.



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: Have a back-up plan - 2 recorders.

2: Preparation makes it easier.

3: It doesn't always go exactly as scripted - this is not necessarily a bad thing.

2) What did you enjoy the most about your experience?

People had interesting things to say - it was good to hear from peers and I enjoyed questioning them.

3) What did you enjoy least about your experience?

Trying to encourage people to talk when they didn't have much to say.

4) What has your experience informed you about your ideas about 'Research'?

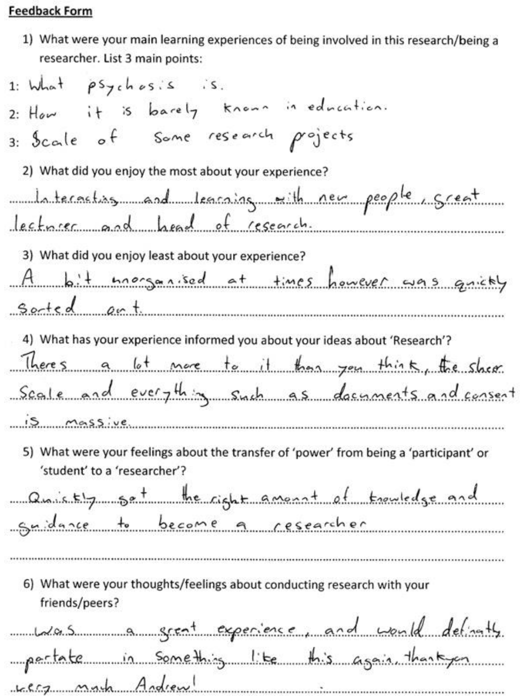
Doesn't necessarily mean collecting information from the internet / books. There are more interactive ways to gain data.

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

It was good to see things from a different perspective, but also difficult to engage the whole group and stay on topic.

6) What were your thoughts/feelings about conducting research with your friends/peers?

I thought it was good because I knew these people well, and they were more willing to participate. Was comfortable around my peers.



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: What psychosis is.

2: How it is barely known in education.

3: Scale of some research projects

2) What did you enjoy the most about your experience?

Interacting and learning with new people, great lecturer and head of research.

3) What did you enjoy least about your experience?

A bit unorganised at times however was quickly sorted out.

4) What has your experience informed you about your ideas about 'Research'?

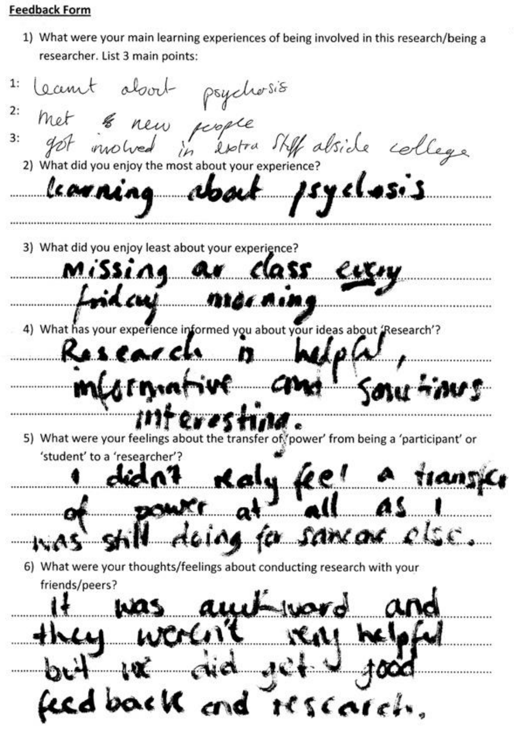
Theres a lot more to it than you think, the sheer scale and everything such as documents and consent is massive.

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

Quickly got the right amount of knowledge and guidance to become a researcher

6) What were your thoughts/feelings about conducting research with your friends/peers?

was a great experience, and would definatly partake in something like this again, thankyou very much Andrew!



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: learnt about psychosis

2: met & new people

3: got involved in extra stuff outside college

2) What did you enjoy the most about your experience?

learning about psychosis

3) What did you enjoy least about your experience?

missing an class every friday morning

4) What has your experience informed you about your ideas about 'Research'?

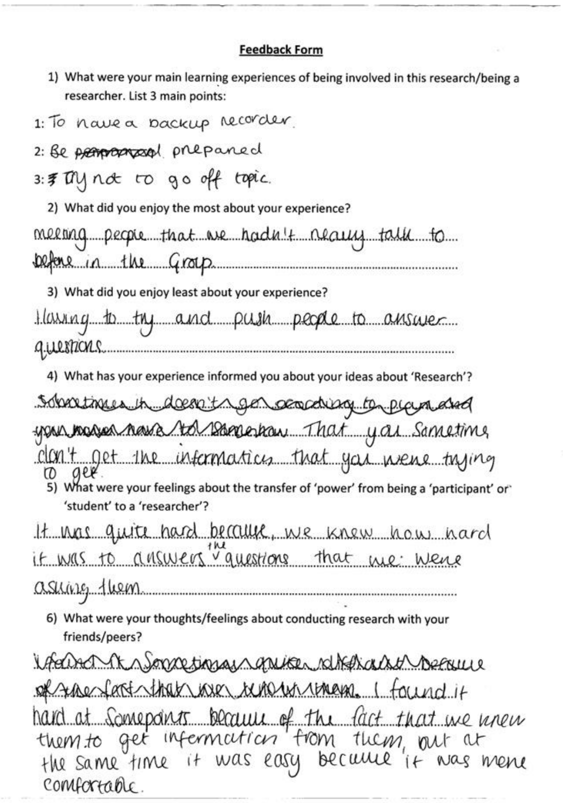
Research is helpful, informative and sometimes interesting.

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

I didn't realy feel a transfer of power at all as I was still doing for someone else.

6) What were your thoughts/feelings about conducting research with your friends/peers?

It was awkward and they weren't very helpful but we did get good feedback and research.



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: To have a backup recorder.
2: Be ~~[illegible]~~ prepared
3: ~~3~~ Try not to go off topic.

2) What did you enjoy the most about your experience?

meeting people that we hadn't really talk to before in the Group

3) What did you enjoy least about your experience?

Having to try and push people to answer questions

4) What has your experience informed you about your ideas about 'Research'?

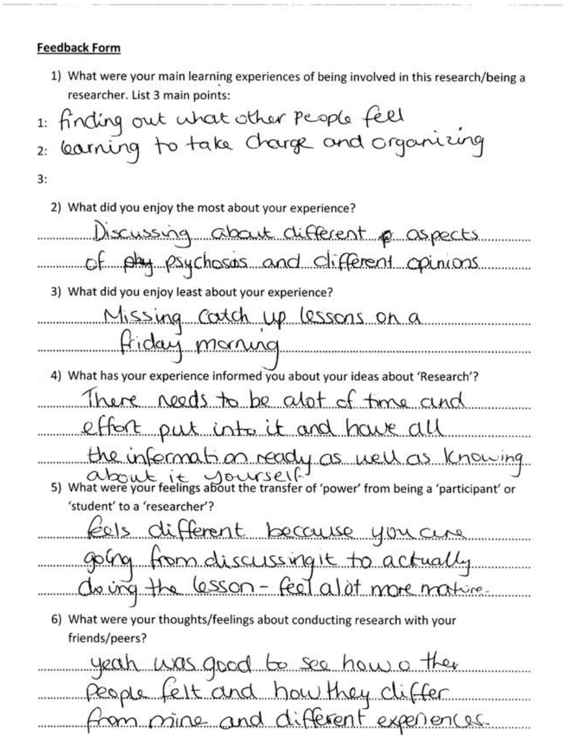
~~Sometimes it doesn't go according to plan and you [illegible] have to [illegible]~~ That you Sometime don't get the information that you were trying to get.

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

It was quite hard because, we knew how hard it was to answers the questions that we were asking them.

6) What were your thoughts/feelings about conducting research with your friends/peers?

~~I found it Sometimes quite difficult because of the fact that we knew them.~~ I found it hard at Somepoints because of the fact that we knew them to get information from them, but at the same time it was easy because it was more comfortable.



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: finding out what other people feel
2: learning to take charge and organizing
3:

2) What did you enjoy the most about your experience?

Discussing about different ~~p~~ aspects of ~~phy~~ psychosis and different opinions

3) What did you enjoy least about your experience?

Missing catch up lessons on a friday morning

4) What has your experience informed you about your ideas about 'Research'?

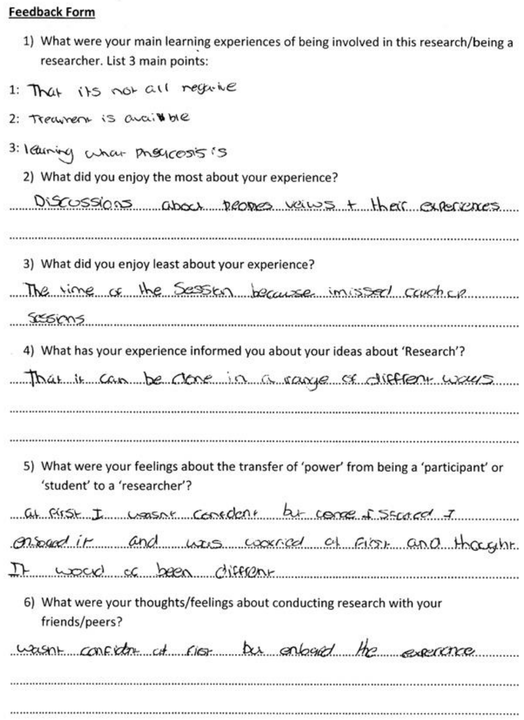
There needs to be alot of time and effort put into it and have all the information ready as well as knowing about it yourself

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

feels different because you are going from discussing it to actually doing the lesson - feel alot more mature.

6) What were your thoughts/feelings about conducting research with your friends/peers?

yeah was good to see how other people felt and how they differ from mine and different experiences.



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: That its not all negative
2: Treatment is available
3: learning what psychosis is

2) What did you enjoy the most about your experience?

Discussions about peoples veiws + their experiences

3) What did you enjoy least about your experience?

The time of the session because i missed catch up sessions

4) What has your experience informed you about your ideas about 'Research'?

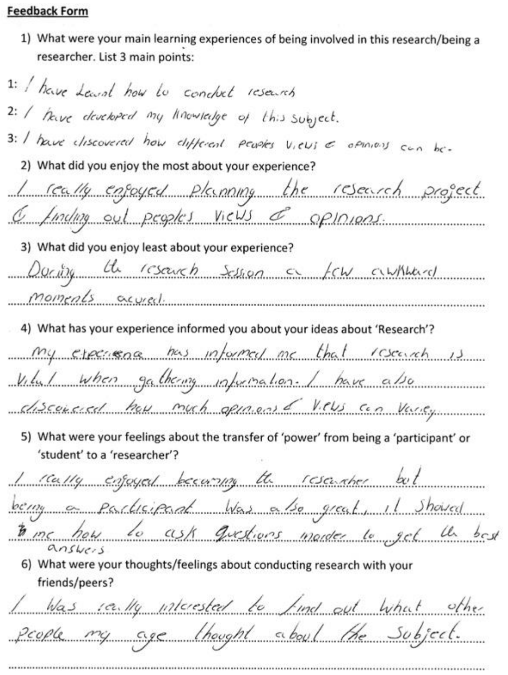
That it can be done in a range of different ways

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

at first I wasnt confident but once I started I enjoyed it and was worried at first and thought It would of been different

6) What were your thoughts/feelings about conducting research with your friends/peers?

wasnt confident at first but enjoyed the experience



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: I have learnt how to conduct research
2: I have developed my knowledge of this subject.
3: I have discovered how different peoples views & opinions can be.

2) What did you enjoy the most about your experience?

I really enjoyed planning the research project & finding out peoples views & opinions.

3) What did you enjoy least about your experience?

During the research session a few awkward moments acured.

4) What has your experience informed you about your ideas about 'Research'?

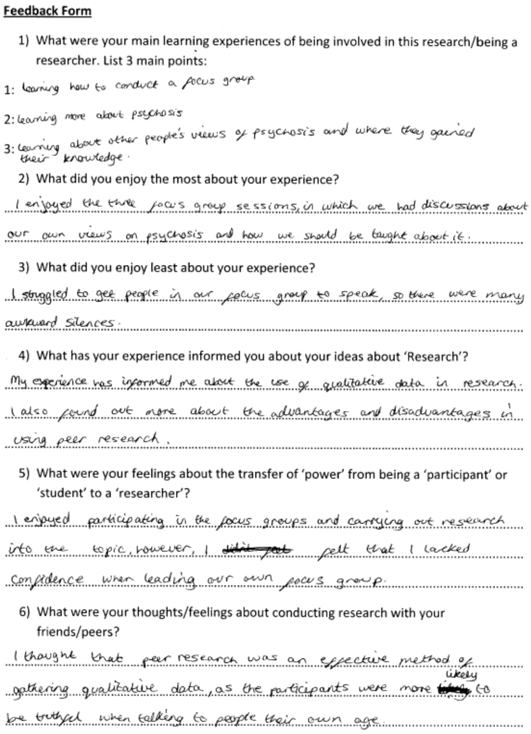
My experience has informed me that research is vital when gathering information. I have also discovered how much opinions & views can vary.

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

I really enjoyed becoming the researcher but being a participant was also great, it showed ~~to~~ me how to ask questions inorder to get the best answers

6) What were your thoughts/feelings about conducting research with your friends/peers?

I was really interested to find out what other people my age thought about the subject.



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: learning how to conduct a focus group

2: learning more about psychosis

3: learning about other people's views of psychosis and where they gained their knowledge.

2) What did you enjoy the most about your experience?

I enjoyed the three focus group sessions, in which we had discussions about our own views on psychosis and how we should be taught about it.

3) What did you enjoy least about your experience?

I struggled to get people in our focus group to speak, so there were many awkward silences.

4) What has your experience informed you about your ideas about 'Research'?

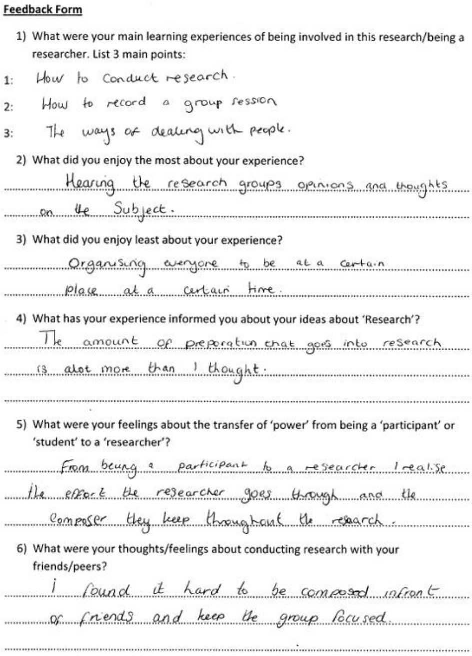
My experience has informed me about the use of qualitative data in research. I also found out more about the advantages and disadvantages in using peer research.

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

I enjoyed participating in the focus groups and carrying out research into the topic, however, I ~~didn't feel~~ felt that I lacked confidence when leading our own focus group.

6) What were your thoughts/feelings about conducting research with your friends/peers?

I thought that peer research was an effective method of gathering qualitative data, as the participants were more likely to be truthful when talking to people their own age.



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: How to Conduct research.

2: How to record a group session

3: The ways of dealing with people.

2) What did you enjoy the most about your experience?

Hearing the research groups opinions and thoughts on the Subject.

3) What did you enjoy least about your experience?

Organising everyone to be at a certain place at a certain time.

4) What has your experience informed you about your ideas about 'Research'?

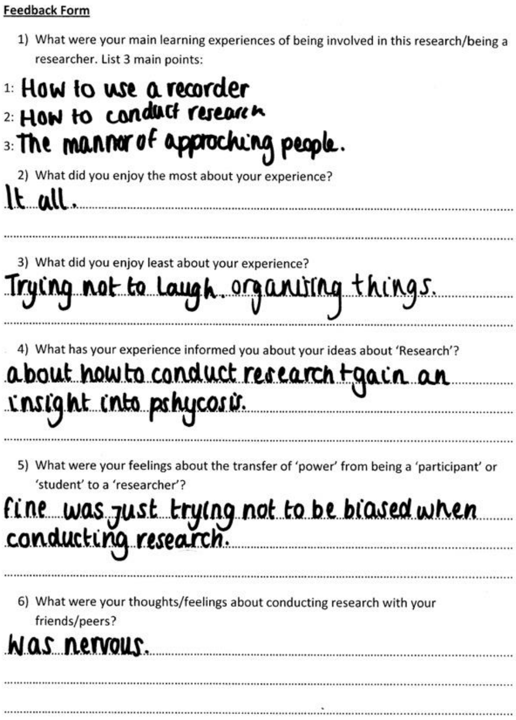
The amount of preporation that goes into research is alot more than I thought.

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

From being a participant to a researcher I realise the effort the researcher goes through and the composer they keep throughout the research.

6) What were your thoughts/feelings about conducting research with your friends/peers?

I found it hard to be composed infront of friends and keep the group focused.



Feedback Form

1) What were your main learning experiences of being involved in this research/being a researcher. List 3 main points:

1: How to use a recorder

2: How to conduct research

3: The mannor of approching people.

2) What did you enjoy the most about your experience?

It all.

3) What did you enjoy least about your experience?

Trying not to laugh. organising things.

4) What has your experience informed you about your ideas about 'Research'?

about how to conduct research + gain an insight into pshycosis.

5) What were your feelings about the transfer of 'power' from being a 'participant' or 'student' to a 'researcher'?

fine was just trying not to be biased when conducting research.

6) What were your thoughts/feelings about conducting research with your friends/peers?

was nervous.

Appendix 9: PR-led resources

Focus Group Session Script

Starting Activity

· To explore young people’s knowledge opinions and views regarding the need for ‘psychosis literacy’
· To increase the awareness and knowledge of psychosis for young people
· To know and respect the views of young people’s knowledge of psychosis
· To explore how young people would like to learn about psychosis

- Blockbusters activity about psychosis to gather and learn what individuals present opinions about psychosis, learn particular stereotypes. 10 minutes.
- First activity: ten general questions about psychosis literacy, asking questions on their views of psychosis, various views of psychosis from different individuals of the group for example where they have got their information from i.e. media, education etc. and how accurate is the source. 15 minutes.
- Second activity: Give the facts on what psychosis is so they have a basic understanding at least. Discussing and explaining what psychosis/ true or false i.e. can it be cured interactive activity, further gathering people’s opinions. 15 minutes.
- Third activity: General discussion, would they be interested in learning about psychosis in education, how it would be taught, include a specific list of methods on how it could be taught i.e. PowerPoint’s, discussions etc. why do they think it’s needed/ not needed be etc. ask individually what people think. 20 minutes.
- Get people’s opinions on how we performed as researchers and how they feel the focus group carried out, did they enjoy it, what could have been improved, were they treated well, confidentiality etc.

Blockbuster Questions
S – What ‘S’ is commonly known as a mental disorder = schizophrenia
A – Who does it affect? = anybody
B- Does psychosis have more negative or positive outcomes on an individual? = both
H – What ‘h’ can be a symptom of psychosis? = hallucination

1) **To find out what young people, between the ages of 16 and 18 already know about psychosis.**

5 min: To explain the research project and discuss and complete consent form

10 min: Starter: Draw an image which you think represents psychosis/schizophrenia for you (Tell participants not to discuss their ideas). Then **discuss reasons why they drew what they drew**. Pictures of various individuals: different age, class and gender and ask whether or not they have psychosis and **reasons why they think that?**

15 min: Activity 1: Post-it notes about what they know about 'psychosis/schizophrenia'. **Discuss what they have written**

15 min: Activity 2: General **discussion** on where they got information about psychosis/schizophrenia and how accurate they think this is.

2) **To find out what young people think would be the most appropriate method of increasing awareness about psychosis.**

10 min: Activity 3: Fact sheet provided regarding psychosis to go through with participants.

10 min: Activity 4: General discussion about what they feel about this topic and whether they think other young people would want or need to learn about it?

30 min: Activity 5: General discussion of different methods:

1) Effectiveness of powerpoints
2) Effectiveness of leaflets
3) Effectiveness of media clips
4) Effectiveness of Internet
5) Effectiveness of drama productions
6) Effectiveness of having a speaker: young person with psychosis, adult with psychosis, family member,

10 min: Any questions.

1. Basically, this is a research project to find out about what young people, between the ages of about 16 and 18, already know about psychosis

2. In case you don't know what we mean by psychosis; two most common forms of psychosis are schizophrenia and bipolar disorder.

3. You should each say your name, from left to right, so your voice can be identified when listening back to the tape.
   Now begin with, we're going to draw around somebody, and write inside the silhouette anything we first associate with psychosis/schizophrenia.

   (Allow time for this activity)

4. Discuss reasons for why they drew what they did. Mention associations they have with:
   Age Gender Class Appearance

- Do you have any strong associations about the age of people who suffer from psychosis?
- Do you think gender is affected by it?
- How about associations with social class?
- How do you think people with psychosis look?

5. There are no right or wrong answers, but why did you think that? Did something/someone influence your associations?
   (Brief talk: post-it notes are next.)

6. Now we're going to give you post-it notes to write down where you got the information from.
   - These don't have to be reliable sources – just anything that contributed to your associations.
7. (Go through each individual post-it and ask who wrote this, and how reliable they think this source of information is.)
   - Did you find out a lot of information from this source?
   - Do you think the information was reliable – did it seem right?
   - Which source of information did you find the most interesting?
   - Did you discuss any of this information with your friends or family?
   - Which source would you each say is the most reliable out of all of those mentioned?

8. We've got some pictures for you to look at. Some of these people have psychosis, and others don't, so basically we want you decide which people you think are most likely to have psychosis.
9. (Discuss reasons why they chose these images)
   -So do you think there's a link between the images you all picked out?
   -Is this because you think age/gender/social class/appearance is affected by psychosis?
   -Do you think it is possible to tell from the pictures, which people suffer from psychosis?

10. We have produced a fact sheet for you, so that you can find out some basic information about psychosis, seeing as some of you know more than others.

    (Read through the sheet with them, one colour of font each)

    -Did you find out anything new from this?
    -Does any of the information surprise you?
    -Is there anything particularly interesting that you found out?
    -Did you think the sheet was well-presented, or was it quite boring to read through?

11. Now we're going to discuss in a bit more detail how you feel about the topic of psychosis.
    - Do you think it is an interesting topic to learn about?
    - Do you wish to know more about it?
    - How about other people your age – do you think they would want to learn about it?
    - Were you taught about it in school?
    - How important do you think it is to teach it in school?
    - Would you have wanted to learn about it at school though?
    - At what age do you think it is appropriate to learn about it?
    - Do you think the topic is a sensitive subject – would you feel comfortable discussing it in school at an early age?
    - How comfortable would you feel talking to your friends about it?
    - Is it something you would discuss with your family?
    - How do you think having more or less psychosis literacy would affect those who suffer from it?

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12. There are a lot of different ways people can be educated on psychosis, and obviously some of them are more effective than others.
    -How useful do you think Powerpoints would be to teach people about psychosis?
    -Do you think you would find them interesting?
    -When you are taught in school do you find yourself able to pay attention to them?
    -Who do you think should present the powerpoint? E.g. somebody who knows a lot about the topic, a sufferer, a friend of a sufferer and why?
    -And at what age group do you think these powerpoints should be aimed and why?

    -How useful do you think leaflets would be in teaching about psychosis?
    -Would they engage the audience?
    -Do you usually find leaflets interesting/ useful?
    -How do you think your friends would react to leaflets? (Would they find them interesting?)
    -Would you be likely to discuss your findings with your friends if they were presented in a leaflet?
    -What age group do you think they would be most effective for?
    -How detailed do you think they should be – should they include a lot of in-depth information or just basic facts?
    -Would you prefer it to be presented to a small or larger group?

-How about media clips – how effective do you think they would be?

- Do you think they would be more entertaining than other sources of information: would you be more likely to listen?

- Have they been effective in the past for other topics?

- What would be the most effective content: would you like to hear from sufferers, people affected by it, doctors, mental health nurses?

- Do you think you would be likely to talk about a video presentation with your friends and family?

- Would this be suitable for a wider audience? Or do you still think there is a specific age group this should be aimed at?

- How long should this video be? How about a short, 5- minute clip vs. a 60- minute detailed video?

-Do you think independent research on the internet would be an effective source of information?

-Would people be likely to look for themselves?

- How would this compare to other sources of information?

- Would this have to be for a more specific age group?

- Do you think your friends would be interested in doing their own research?

- Is independent research something you would be willing to do, and have you done this in the past?

-Have you ever watched a drama production to find out information? (and was this effective?)

-Is that something you would be interested in?

-Would it keep the audience engaged or would they find it boring?

-What age group would this be appropriate for?

-In what context would you watch this (eg. college production?)

- What about the length of the production; should it be long or short?

- How many people should it be aimed at – a smaller or a larger group, and would this affect your ability to pay attention?

-How effective do you think having a speaker would be?

-Who do you think this speaker should be?

-Would you prefer it if they were speaking to a large audience, or a smaller group? Is there an idea number?

-Should this be arranged in colleges and schools for everybody?

-Do you think it would be effective in educating people?

-At what age would this be appropriate and in what detail?

-How do you think your friends would feel about this?

-Would this make you likely to discuss the topic with friends and family?

-And would you feel comfortable with it?

Can anybody else think of another method that could be used?

Does anybody have any more questions?

(Possible response)

Ok, we'll finish there.

Fact sheet

‘Psychosis’ is a term used to describe a combination of symptoms including:

-Delusions – unshakeable beliefs that are untrue, eg. a plot to harm, or being taken over by aliens.

-Hallucinations – when someone sees, hears, smells or feels something that isn’t actually there. Most commonly people hear voices, and these are real to the person experiencing them.

-Confusion

-Disturbed thinking

-Change in feelings and behaviour

-Thought disorder – when someone is not thinking straight and it’s hard to make sense of what they’re saying.

-People may also have symptoms such as feeling sad and irritable; have difficulty sleeping, neglecting appearance, little display of emotions, and many others.

Psychotic episodes can vary in length, and often people are unaware they are unwell. They often believe what they are experiencing is actually happening to them. It can affect people of all ages, but becomes more common as you reach young adulthood.

Symptoms of psychosis can occur when people are suffering from various mental health conditions for example; schizophrenia, bipolar disorder, schizoaffective disorder, dementia, some forms of personality disorder and Parkinson’s disease.

Psychosis" should not be confused with the term "psychopath". The two conditions are very different. Someone with psychosis has an acute (short-term) condition that, if treated, can often lead to a full recovery.

The causes of psychosis are not fully understood, but may be due to, abnormalities in the chemistry of the brain, causing changes in thoughts, feelings and behaviour.

Around 1 in 50 people will experience a psychotic episode in their lifetime.

Why is it important to have mixed gender groups?

-A range of opinions will be collected from each gender, to give both male and female points of view. At the present stage of the research, we have only had a female point of view.

Why are only 4-6 people involved?

-To provide enough information for qualitative data to be produced. If there were more people, there would be less opportunity to share views and opinions about the topic.

If you require any further information or have got any questions about the research please contact the principle researcher:

Andrew Ramtohul

Andrew.ramtohul@northumbria.ac.uk

Listen up : young people's views to help shape education to support psychosis literacy

Why are we considering the topic of psychosis literacy?

To look in detail at the views of 16-18 year olds, about psychosis literacy.

Psychosis literacy is increasing awareness, knowledge and understanding of psychosis.

This topic has been chosen for us by Teesside University, to find out what young people know about psychosis, and how they would want to be taught about it.

Why are young people our participants?

-To get a view, collectively from young people, about psychosis and how they feel it should be dealt with in schools.

-Young people are part of the education system, so they would be directly affected by the information provided regarding mental health issues.

Aims and objectives:

-To find out what young people, between the ages of 16 and 18 already know about psychosis.

-To find out what young people think would be the most appropriate method of increasing awareness about psychosis.

Peer Research Methodology

We are conducting research with our peers. 'Peer' means students studying A levels at our college aged 16-18.

Benefits of using peer research:

-People will be more likely to truthfully express their own views with their fellow peers.

-People will feel more comfortable and enjoy the session.

Risks of using peer research:

-Language may be used which will purposefully cause offence to others– this will not be tolerated within the focus - group and the session will be stopped.

-Some of the issues discusses are sensitive. If you feel you would not be able to cope in these discussions, be aware this may not be appropriate for you.

-There may be a possibility that confidentiality could be breached—people should be clear of what they are allowed to say, with information about individual people remaining anonymous.

Confidentiality

-Individual names should not be mentioned within the focus group, in order to maintain confidentiality of others.

-Participants should be aware that they can withdraw from the study at any time, however, it is not possible for them to withdraw statements made prior to that point.

-Confidentiality would be breeched if statements were made which indicate that harm could be caused to themselves or other people.

What is going to happen to the information collected?

-The information collected within the focus group will be audio taped and transcribed by the principle researcher Andrew Ramtohul, as part of the study.

-The information will be collected and stored securely at the University (password protected) and held for a minimum of 5 years (according to Data Protection Act 1998)

Confidentiality

- No names are to be mentioned whatsoever, you may use terms such as "I know of someone" or "I have heard from" etc. So confidentiality isn't broken.
- No discussion of personal issues, such as family problems or themselves.
- Respect other peers opinions and ideas and maintain confidentiality in the group and participants will remain anonymous throughout the discussion.
- Discussions will be an hour long and will be audio recorded throughout to gather opinions for our research.
- Audio recordings will be held securely at Teesside University in accordance to the data protection act 1998 and will be held for a minimum of five years.
- Participants will be asked to complete a consent form giving their permission to take part, be audio recorded, and have their opinions used in research.
- If any confidential information is breached then the discussion will be stopped
- If from the information you have told us we have found out that you or others are at harm, we have the obligation to inform the safeguarding team in college.

If you have any concerns or questions about the group discussions or psychosis literacy, please contact;

Head of Research - Andrew Ramtohul

Email: a.ramtohul@tees.ac.uk

Listen up: Using young people's views to help shape education to support 'psychosis literacy'

What is Psychosis literacy?

- The term psychosis is a mental health condition that includes schizophrenia.
- The term literacy is about the understanding and knowledge of any topic, in this case psychosis.

How are we going to achieve our aims.

- Selecting our participants with an equal ratio of gender, to get a male and female perspective of psychosis literacy.
- Participants will be aged between 16—18 that are currently in education. This is because we are looking for young peoples opinions on psychosis literacy, and see if it should be in education or not.
- Hopefully participants will feel more comfortable talking with fellow peers and be more open sharing their opinions.
- There will be an informal group discussion between four and six participants with two to three peer researchers.

Aims of the study

- To explore young people's knowledge opinions and views regarding the need for 'psychosis literacy'
- To increase the awareness and knowledge of psychosis for young people
- To know and respect the views of young people's knowledge of psychosis
- To explore how young people would like to learn about psychosis

Why are we interested?

- We have been asked to research psychosis literacy and to see if we can fill a gap in the education system regarding psychosis.
- This is because we fit the criteria of being aged between 16 to 18.
- We are also health and social care students and are wanting to find the views of people outside our subject area to see how their views differ from ours.

Potential Benefits

- To find out what information peers already know about psychosis literacy
- To increase awareness of psychosis literacy
- To understand how we can put it into education
- To find out what methods students would prefer to be taught psychosis literacy
- Socialising with peers and new people and enjoy discussing psychosis.

Potential Risks

- Peers may not take the research project seriously, therefore need to make it clear that it is a professional research task.
- People may feel uncomfortable or may feel distressed discussing psychosis, if this is the case then we need to ensure students sensitive to this subject are not chosen to participate.
- There is a risk that offensive and inappropriate language may be used, therefore we need to ensure that it is not directed at other peers or researchers.

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