



**Geographies of Impulse:  
Tourette Syndrome and the embodied  
experience(s) of public spaces**

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## **i. Abstract**

Tourette Syndrome, characterised by impulsive vocal and motor tics, is of increasing interest to researchers, and the experiences had by Tourettic folks are distinct. With the nuance and complexity of ticcy experiences, an interdisciplinary approach is required. Through taking an interdisciplinary crip approach to disability, drawing upon participatory practices, medical sociology, geographical, bioethical, and crip influences, the thesis aims to bring to light these distinct experiences that are had by Tourettic adults in and around public spaces, in both the physical and digital realms. Through careful analysis of the stories told by the project's participants, the research found that experiences in and around public spaces occur in ways that relate to chance encounters. The material and immaterial elements of public spaces contribute the Tourettic encounters that might occur in them, and the way that Tourettic adults manage and strategically respond to these encounters in creative ways is distinct from non-disabled people. These processes highlight the various ways in which Tourettic people are othered in both physical and digital public spaces, which contributes to increased levels of loneliness within the Tourettic community. With loneliness a distinct part of the Tourettic experience, the research highlights the need for better spaces of support for adults, and problematises those that already exist. In doing so, it offers the example of the zineing workshop space as a site for the facilitation of solidarity and community building within the Tourettic community. The results of the research offer steps forwards in producing data that highlights the need for further consideration of adults with Tourette Syndrome, not only in regard to the design and provision of support services but also conceptually within academic research spaces. In doing so, it also offers the case for a geography of impulse, whereby concepts of impulse can be applied more broadly in the study of public spaces and the processes that happen within and around them.

## ii. Acknowledgements

The process of completing a PhD has been a wild one to say the least. From even before the programme started, I was faced with the ableist realities of the university. So much so that it has now led to my post-doctoral employment on a project focused around dismantling the ableist university. Perhaps I should be grateful? Perhaps I should say “well it all worked out in the end”. But no. I understand that the acknowledgements section for a PhD thesis is assumed to be a collection of folks you’re grateful for, and a general space of positivity. However, I think I would be doing a disservice to not specifically acknowledge the intense struggles with an ableist academia I’ve experienced throughout this process. I remember joking with people about making my acknowledgements a *hit list* of all the people and processes that have made things unnecessarily more difficult for me throughout the course, and in a way I am still tempted, but I will spare this for now. Ultimately, if you’re reading these acknowledgements, please know that the acknowledgements, the research, and the final thesis are all underwritten and contextualised by intense and upsetting experiences of ableism. Perhaps this adds another layer of meaning to those I thank here...

Whilst this process has been incredibly difficult, emotional, and in all honesty traumatic at some points, I would not have gotten where I am today without the support of friends, family, loved ones, colleagues, and a whole lot of strangers I met over the Internet (which feels fitting given the strong focus I have in this thesis on the value of digital spaces).

Firstly, I want to thank every single one of the participants of the project for giving up their time to be involved. Every single interview, email exchange, focus group, and piece of art in the project taught me more than you could ever know. This is your thesis. Without your stories and your willingness to be vulnerable in sharing unfiltered experiences with me, this thesis would not exist. Again, this is *your* thesis. My name might be written down as author, but I hope you can look at this and feel the same pride that I do, knowing that this belongs to you too.

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neurodivergent researcher to try and make some sense of the chaos that is academia with. Additionally, I would like to thank the NINEDTP and the ESRC for funding this research.

I previously mentioned that I was thankful for strangers on the Internet, some of whom I do not even know real names but rather know them by their social media handles or usernames. In fact, some of these folks have truly become members of my chosen family and have already been acknowledged here. In 2022, after I began working from home more due to accessibility reasons such as people's refusal to mask, stigmatised responses to Tourette Syndrome, and so on, I found myself missing being physically *in* an office environment with pockets of conversation, coffee breaks, and so on. I stumbled across a website called Twitch, which is primarily known for its live-streaming gaming-focused content. However, I discovered a wonderful community of people providing virtual offices and co-working spaces more generally on the platform. I began streaming these co-working spaces myself and found that I was able to get more work done through body doubling and the sense of accountability that stream viewers held me to. Since May 2022, the community of co-workers (students and otherwise remote workers) has grown significantly, and between platforms we now have a large community who hold each other to account, encourage each other when things get tough regarding work and study, and generally just make the remote working process a lot more enjoyable. So thank you to my wonderful streaming community – for all those who have been engaging with the channel, to some extent I feel like I owe a lot of this work to you. The support I've been shown when facing financial or emotional challenges throughout the course of my PhD has been incredible, and I will be forever grateful.

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I'm really not sure what is considered most appropriate when it comes to ending a PhD thesis acknowledgements section (though I suppose mentioning my academia anti-acknowledgements hit list that will never see the light of day is unlikely to align with those expectations). However, perhaps a form dedication is due? I want to dedicate this to folks like me - disabled who have been taken for granted and been blocked from academic spaces. Disability research happens in structurally ableist spaces, and this means that folks like me oftentimes don't have the opportunity to contribute to knowledge production in academic spaces. This is dedicated to everyone who's been excluded, and to a hopeful future where disabled people are not excluded from academic spaces.

#NothingAboutUsWithoutUs

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## Chapter 1. Introduction

*Around 6 years ago, I sat in a seminar for my MA degree in Cultural Geography, as the instructor lectured about the body and how bodies navigate space. She stated that the body's movements are choreographed, each movement being made intentionally and having purpose that arose in response to external stimuli. As somebody with a diagnosis of Tourette Syndrome and therefore with limited control over my own body, this sparked my interest. I grew increasingly frustrated knowing that the only literature I could find didn't feel like it made any sense to me, as somebody who experiences impulse arising from Tourette Syndrome and tics. In an attempt to understand my own body, I ran with this idea of impulsivity in my MA dissertation, and it was revealed to me that there was much more to this line of inquiry than I had initially thought...*

In their paper outlining the work that has been done by scholars to engage with a relational approach to disability, Hall & Wilton (2017) conclude by calling for further empirical attention to be paid to the diversity of “embodied experiences that overwhelm any binary opposition between a normative ‘able-body’ and its disabled other” (p740). Calls such as this have also greatly encouraged the formation of this research, as it attempts to answer the call for further attention to this, and in a particularly turbulent time at that! It is a particularly turbulent time in regard to Tourette Syndrome discourse, with accusations of faking for social media attention, and stigmatised media and research representation of Tourettic people themselves being increasingly common. Questioning the binary between choreographed and uncontrolled movement in my own and others' tourettic body(-ies) could contribute to this call.

We are currently living in a time where Tourette Syndrome is increasingly on people's radars, more so than ever before. In the wake of the COVID-19 pandemic, fears surrounding increased social media use and its supposed impact on young people 'catching' Tourette Syndrome began to emerge (Forsyth, 2021; Giedinghagen, 2022; Hull & Parnes, 2021; Kennedy, 2020; Olvera *et al.*, 2021). My own experiences began to change, with GP's beginning to ask if I used TikTok at every single check-up, whether the appointment was related to Tourette Syndrome or not. *You say you think you have a chest infection? I noticed you have Tourette Syndrome, do you use TikTok?* A conversation that seems far too common to me over the last 4 years.

Whilst Tourette Syndrome is definitely something that more people have heard about today than ever before, the understandings of it are particularly stigmatised. Tourettic people are continuously harassed as they go about their everyday lives (Centre for Disease Control and Prevention, 2024; Stofleth & Parks, 2022), and it appears that there is minimal understanding of the nuanced experiences that Tourettic people have. There is a geographical element to the ways in which Tourettic people are harassed, and it is significantly influenced by the ways in which various public places are imagined and constructed, both abstractly and in terms of built environment and design. This research attempts to provide some further, much needed, nuance. In the discipline of geography especially, the framework or lens of space and place is used to inquire into various topics of interest. Combining my interest in Tourette Syndrome and the need for nuanced consideration with the approach of geographical grounding in space and place is one way that Tourette Syndrome and its nuances has not been considered in such depth before.

This next section shall offer an introduction to Tourette Syndrome, along with a short review of trends in TS research in order to offer context for the project.

### **1.1 Contextualising Tourette Syndrome**

The way that this thesis approaches public space and embodied experience is through the lens of Tourette Syndrome. Tourette Syndrome is a disability or neurodivergent condition medically defined as a heterogeneous disorder (Efron & Dale, 2018), characterised by multiple motor and at least one vocal tic that have persisted for at least one full year that cannot be linked to another diagnosis or drug-use symptom (Gill & Kompoliti, 2020). A motor tic is a physical tic, which might include twitching, facial grimaces, or other movement-based tics. A vocal tic is one which produces sound, whether full words and sentences or not. Tics and Tourette Syndrome have been of interest to neurologists and other medical researchers alike for many years (Cavanna *et al.*, 2017; Cavanna & Seri, 2013; Isaacs & Riordan, 2020; Kano *et al.*, 1998; Krah, 2002; Kwak *et al.*, 2003; Robertson, 2023) and more recently has been of interest to social scientists and medical humanities scholars (Beljaars, 2022; Beljaars & Bervoets, 2021; Bervoets *et al.*, 2022, 2023; Davis *et al.*, 2004a). This section of the introductory chapter shall provide some context surrounding Tourette Syndrome, ahead of literature reviewing, methodological outlining, analysis, and discussion to come later in the thesis.

Tourette Syndrome has a history of being a particularly stigmatised disability, and recently has been subject to a lot of media coverage that has influenced Tourette Syndrome discourse. AJ Hughes (1996) wrote autobiographically about his experiences of Tourette Syndrome. One extract in particular speaks to some of the stigma experienced:

*“Perhaps the worst thing that ever happened to Touretters like me was the emergence of psychoanalysis in the 20<sup>th</sup> century. Since I was 19, I have been to nearly a dozen psychologists and psychiatrists and general physicians, looking for answers. I have been advised to meditate, because spiritually my Karma was not ‘in synch’ with the cosmos. I have tried psychotherapy, because my tics were apparently an outward manifestation of an inward need to express myself in socially inappropriate ways. I have been told that praying would solve the problem. It didn’t (There may be some kind of spiritual poetic justice in the religious dead end, especially because in the Middle Ages it was fairly common practice to burn Tourettic people at the stake as heretics. Apparently, the local priests and townspeople assumed that such a person was possessed by the devil). Then there was acupuncture, a futile remedy, and a visit to a nutritionist. Finally, there was group therapy, because I needed some ‘social readjustment’ to deal with improving my ‘transactional skills’” (p318)*

It's clear to see that stigmatisation has been written about in detail – and been written about in stigmatising ways itself - and as something written and published in 1996, my experience of Tourette Syndrome as someone who was born in that very year is concerningly similar. In more recent years, stigma has not only remained in regards to accusations of Tourettic folk being possessed by demons, as poorly behaved and socially inappropriate children, and so on, but additionally stigmatised assumptions surrounding Tourette Syndrome as a mass-sociogenic illness spreadable via social media like the *common cold* (Firecracker Films, 2022; Müller-Vahl *et al.*, 2021) have come into existence. Stigma more recently has been a concept through which academics have explored Tourette Syndrome extensively (Bervoets *et al.*, 2022; Conelea *et al.*, 2022; Cox *et al.*, 2019; Malli *et al.*, 2016; Malli & Forrester-Jones, 2021), and has been written about as a key element of the ways that Tourettic people experience the world.

Contextually then, it is important to acknowledge that Tourette Syndrome has been stigmatised by the general public, media, the medical profession and academics alike for many years. Tourette Syndrome, even to this day, is considered taboo and this significantly influences the research being conducted and the services being provided for Tourettic people.

## **1.2 Stigmatising Trends in Tourette Syndrome Research**

There are some particular trends that have come to light regarding the study of Tourette Syndrome, both in the context of medical and social science research. Tourette Syndrome is still very much a stigmatised diagnosis, and this is reflected in many of the current trends in TS research. This section shall address these trends, considering first the medical trends before addressing social science trends, and those that also span across both categories.

### **1.2.1 Infantilisation of Tourette Syndrome (children and parents as a focus)**

Many medical professionals and much of the medical literature states that in order to receive a diagnosis of Tourette Syndrome, the onset must – or typically – occur prior to the age of 18 (Andrén *et al.*, 2021; Malli *et al.*, 2016, 2019; Robertson, 2003). Additionally, even when this is not specified, when discussing statistics for TS diagnosis, the language is most commonly referring to how many *children* are diagnosed (Caurín *et al.*, 2014; Olson, 2004; Rapoport & Castellanos, 1992). What follows is a significant skew towards focusing on research into children and Tourette Syndrome, as can be seen across the current Tourette Syndrome literature (Andrén *et al.*, 2021; Bawden *et al.*, 1998; Boudjouk *et al.*, 2000; Stokes *et al.*, 1991; Storch *et al.*, 2007; Wand *et al.*, 1993). With such a strong focus on children, there have been implications that have led to the infantilisation of adults who are diagnosed with Tourette Syndrome. Much of the analysis and discussion to follow in this thesis is contextualised by this infantilisation.

Much has been written about Tourette Syndrome and experiences of stigma in particular. It has been reported in research that there have been increased levels of isolation and loneliness, along with experiences of bullying (Cox *et al.*, 2019). This is all encouraged and further facilitated by the existing misconceptions about the diagnosis (Malli *et al.*, 2016). Studies have considered the way that people are bullied and treated unfairly in educational settings in particular when considering isolation and social stigma, with students being reported to engage in physically assaulting Tourettic children (Cutler *et al.*, 2009) or Tourettic children simply being left out of games and sports teams (Grace & Russell, 2005). A common theme across literature has been identified by Smith *et al.* (2015) as negative experiences that relate to socio-cultural issues and misunderstandings of Tourette Syndrome. These cultural issues could include references

to social stigma, bullying, acceptance and integration into communities. The same goes for concerns for the future, and personal identity. However, what Smith *et al.*'s review fails to take note of is the way that almost all of the considered papers are concerning the experiences of under-18s and/or their parents/carers' proxy descriptions of their experiences. The work into the experiences of children and young people is incredibly important, and it is key here to acknowledge that this work is not to be completely disregarded. Much research has been conducted in ethical and participatory ways. However, what for the consideration of adults? It is key to also acknowledge that whilst this work is important, many of the outcomes and suggestions for development concern specific under-18 contexts. For Tourette adults, isolation and stigma is not experienced through school-yard bullying and exclusion, but in other ways that are not necessarily considered in the current literature, going beyond into public spaces more broadly speaking. Experiences of isolation and stigma go beyond the school context and persist into adult experiences too. It is in the move towards the consideration of public spaces more broadly that the need for geographical approaches to Tourette Syndrome research come into play here. Suggestions for how to help children with a diagnosis of Tourette Syndrome have been explored in new and upcoming research at a doctoral thesis level by researchers such as Babbage (2021) who explores digital intervention tools for young people with TS, or by Warnock (2022) who offers suggestions for schools to better support Tourette children in educational contexts. There is, however, minimal literature that relates to adults, and 1.3 shall address this gap, and provide some examples of the scholars currently working to fill it.

### **1.2.2 'Treatment' versus Experience**

As with many disabilities and neurodivergences, a significant portion of Tourette Syndrome discourse centres around the *curing* or *controlling* of the condition. The language used in literature to refer to this is *treatment* (Iverson *et al.*, 2023; McNaught & Mink, 2011; Singer, 2010). An expectation of treatment and cure by participants underwrote this project, and when reading the information sheet and consent form some were surprised that treatment, management or cure was not something this project aimed to work towards. This will be explored in Chapter 3, and ultimately acted as context for the ways in which participants engaged with this doctoral project. A significant amount of literature concerns the tourette tic(s) as behavioural, meaning that this *treatment* is

oftentimes framed as an attempt to change the *behaviour* of tourettic patients. The infantilisation of Tourette Syndrome patients contributes to the consideration of tics as compulsive actions (read: naughty children who are misbehaving) rather than humans who tic *impulsively*. The behavioural approach to TS treatment might be through cognitive behavioural therapy (Frank & Cavanna, 2013; Fründt *et al.*, 2017) or through other self-directed ‘compulsion control’ approaches such as the Neupulse device<sup>1</sup> (Maiquez *et al.*, 2023).

With a significant focus on *treatment*, the experiences of tourettic people have not been so significantly written about until recent years. Notable contributions have been made by a small group of academics that span multiple disciplines. Diana Beljaars, Jo Bervoets, and Hannah de Jaegher have published about experiences of Tourette Syndrome (Beljaars, 2017, 2020, 2022; Beljaars & Bervoets, 2021; Bervoets *et al.*, 2021, 2023). Beljaars in particular takes a geographical approach to the study of Tourette Syndrome, and the performance and material interactions that tourettic people have with their environments (Beljaars, 2020). Further to this, her recent monograph ‘Compulsive Body Spaces’ Beljaars (2022) attempts to posit “compulsion as a problematic phenomenon in academia because of its anti-humanist, a-moralist, and irrational connotations, because it demonstrates a side of the human we do not like and that is problematised and medicalised in Western societies” (2022: 33). By focusing on the experiences of Tourettic people rather than on the curing and treatment of tics, for example, it brings to attention the irrational and somewhat feared ideas of impulse<sup>2</sup> and tics and how they link to our humanity. There is a need here demonstrated by Beljaars to look at experience, but also a need for the consideration of moving beyond the paradigm of Tourette Syndrome as a problem to be fixed when conducting that research.

### 1.2.3 Filling the gap

Perhaps it could be argued that a gap exists in the literature – though it is slowly beginning to be filled – that concerns not only experiences of Tourette Syndrome by the tourettic person themselves, but with specific focus on adulthood. By de-infantilising

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<sup>1</sup> The Neupulse device is a wearable wrist-device that administers median nerve stimulation (also known as a shock), and is a device that is designed to minimise tics through the self-administering of these stimulations. At the time of writing, the device is undergoing clinical trials.

<sup>2</sup> Whilst Beljaars uses the idea of compulsion and compulsivity in her writing, I argue that *impulse* is a much more accurately representative word for what she is describing in her published works. As a result, I have changed this term to more accurately reflect my points.

Tourette Syndrome and through considering direct adult experiences of Tourette Syndrome, scholars can contribute to the unsettling of what we consider it to mean to *be human*, as per Beljaars' (2022) monograph. A move beyond medicalised approaches to Tourette Syndrome, and beyond academic paediatric-centred assumptions of Tourette Syndrome and tic disorders more generally speaking, can reveal a new geography of impulse that perhaps is not only applicable in the case of Tourette Syndrome, but to humanity more generally speaking. Returning to Hall & Wilton's (2017) call to push back against binary understandings of disabled – non-disabled, there is some work that is beginning to focus on experience and give representation to Tourettic folk themselves. This work particularly considers adults and their experiences, rather than taking the traditional 'curing' or 'treatment' and paediatric focus of others.

Taking a statistical approach, Conelea *et al.* (2013) found that across a large sample of Tourettic adults, the assessed quality of life was significantly lower than for non-Tourettic adults. Despite this publication from over a decade ago, there is still only a minimal number of researchers who publish work surrounding adulthood experiences of Tourette Syndrome. Again, Beljaars' work is significant here. However, there are a select group of researchers who are also making attempts to move beyond the infantilisation and 'treatment' of Tourettic folk. Malli *et al.* (2019) discuss loneliness and the distinct experiences of loneliness that Tourettic adults face – something which will be discussed in significant depth in Chapter 5 of this thesis – whereby they consider adult experiences of self-stigma, self-identity perception, and the ways it impacts the day to day lives of tourettic adults. Malli and Forrester-Jones also worked to explore stigma and othering in Tourette Syndrome. They write how "Jokes, humour and trivialisation were identified as factors that insidiously perpetuate discrimination [for Tourettic adults], but also create a unique form of stigma that is disguised by a veneer of light-heartedness and allows societal inertia, urging clinicians to acknowledge the social complications related to a TS diagnosis (Malli & Forrester-Jones, 2022: 893). Whilst much of this work is being done by non-tourettic researchers, I feel it important here to bring to attention the doctoral work that tourettic scholar Danni Phoenix-Kane is engaging in. In short, Phoenix-Kane's research concerns the diagnostic journey, lived experience, and support for adults presenting with tic disorders such as Tourette Syndrome across the UK. Her forthcoming thesis focuses on adulthood diagnosis, and she is currently working with artists and

researchers to create audio-visual artistic pieces to represent a reframing of Tourette Syndrome in the public sphere with a focus on adulthood experiences (Godman *et al.*, 2024 – manuscript in preparation).

Geographically speaking, there is also a gap present when it comes to crip inquiry into public spaces that spans physical and digital spaces, and considers the space of the support group. Notably, in *The Internet in Everyday Life*, Haythornthwaite & Wellman (2002: 26) refer to how online support groups can offer “much needed support”, but a discussion of the specific nuances of the support group are not within the scope of the book. Whilst the book refers to them within the concept of everyday internet use or everyday digital space-facilitated interactions, focus on disability and concepts of loneliness, belonging, community and solidarity are not explored. Furthermore, Hall and Bates explore the ways in which a disability support group might be one of the few care sites that exists within a given city, and begin to touch on the relevance of these spaces for disabled folks (Hall & Bates, 2019). Whilst conceptualised as important and as sites of care by geography scholars, the support group space has not been conceptualised as a public space. The nuances and ways in which these spaces echo encounters in and around other public spaces as they are more traditionally understood are more explicit to those of us who occupy both kinds of spaces. In the instance of Tourette Syndrome, there is currently at the time of writing no geographical engagement with Tourette Syndrome that considers these spaces as publics, or that conceptualises them in distinctly *Tourettic* ways.

This thesis fills this gap by conceptualising public spaces to be inclusive of support group spaces, both in the physical and digital realms. A crip, adult-focused, non-medical approach to Tourette Syndrome is taken in this research. In doing so, it draws together healthcare and geographical understandings of Tourette Syndrome and public space in order to fill these aforementioned gaps.

### **1.3 Moving forwards**

With the aforementioned in mind, this chapter has provided an introduction to Tourette Syndrome and offered context and justification for this project’s importance. Moving forwards, Chapter 2 will outline the existing literature within the field of geography that concerns public spaces and disability, and how it relates (or does not relate) to Tourettic experiences. The chapter explores relevant literature in depth, including key

concepts that offer foundations for this work to build on. It explores non-representational theory, and the idea of the *encounter*, before considering different models of disability that give context to the arguments to follow. It then traces influences through queer studies to crip studies. Ultimately it outlines how geography can benefit from crip intervention when it comes to disability and public space, and highlights the ways in which this thesis crips non-representational theory and post-phenomenology as concepts that this research has been built on.

Chapter 3 concerns the methodology of the research project, starting off with a contextualisation of the study, and an outline of the key research questions and how they are relevant to geography as a discipline. It gives context as to the collaborative nature of the research, in that it was done in collaboration with a Hull-based charity - *TIC Hull* - and their role in planning and supporting the research is outlined here. From here, it moves on to highlighting the overall aims of the project in that it attempts to fill a significant gap in the literature, and provide some suggestions moving forwards in regard to service provision and TS-based research. It then moves on to considering the ontological backing of the research, elaborating on some of the work in the literature review, highlighting some of the participatory-aligned approaches taken within the research. The chapter then continues on to give context for the ways in which the COVID-19 pandemic has underwritten various parts of this research, before highlighting key information regarding the sampling and demographics where some key participants that speak to the research throughout the thesis are introduced in more depth. Data collection and analysis approaches are outlined, before moving on to acknowledge some restrictions and limitations that exist within the methodological approaches taken. The chapter ends with an in-depth positionality statement that gives context as to my own lived experience with Tourette Syndrome.

Chapter 4 focuses on the concept of the *Chance Encounter* and considers the social dynamics of the impulse that it argues is inherent to Tourette Syndrome and the ways in which it is experienced. The chapter uses research participant experiences in order to introduce the concept of the *chance encounter*, before considering the ways in which the premonitory urge associated with Tourette Syndrome is key in influencing these chance encounters. To do so, it highlights examples of *pockets* of opportunity for tourettic impulse to manifest in, such as in spaces with a perceived sense of anonymity, the

response to loud sounds as opportunities to remain anonymous in, and opportunities for *threat*. It then considers the relevance of communication and refers to the verbal and non-verbal dialogues that occur between affective bodies in order to give backing to the ways in which the chapter argues that chance encounters are facilitated, and highlights the creative everyday strategizing that is undertaken by tourettic people. It argues that in this regard, the encounters had within, and experiences of, public space are particularly distinct for tourettic people.

Chapter 5 extends some of the arguments and examples highlighted in Chapter 4, which focused on physical public spaces, into the digital realm. It conceptualises *communities* as a form of public, and uses the case of the Tourette Syndrome support group in particular to demonstrate this. The chapter particularly concerns the distinctive experiences of loneliness and isolation that the Tourettic community have in order to highlight the importance of, and the need for, increased sense-of-community, support groups, and more generally support that is needed for Tourettic people. It uses participant experiences of loneliness, isolation, and lack of available in-person support or service provision to explain the digital shift in TS support, and uses this to move arguments about chance encounters and experiences of public space into the digital realm. In doing so, it highlights the uneven workloads and power dynamics that exist in this regard, critiquing the additional labour that is required to access support, and in many cases facilitate it themselves, for adults with Tourette Syndrome. From here, the conversation shifts beyond digital community and sense-of-belonging, and considers un/belonging and othering that happens within the Tourettic community in these spaces. In conclusion, it highlights some hope for the future, reassuring us that community and sense of belonging is produced and practiced in a huge variety of ways, and that disability intimacy can be found in these spaces. It argues that perhaps inherently distinctive experiences of loneliness and isolation are not the only option for Tourettic people.

Following on from this, Chapter 6 returns to some of the methodological aspects of this research. It focuses on the ways in which creative approaches to research and spaces such as creative zine-making workshops can facilitate solidarity and sense-of-community, and offers some hope for the future of Tourette Syndrome discourse. The chapter explores the value of creative and collaborative methods in documenting Tourettic experiences, but focuses particularly on the participants' reflections on taking

part in the workshop shared with me through follow-up interviews. Returning to ideas of the chance encounter that might happen within public spaces, this chapter situates creative geographies in solidarity and solidarity-aligned practices, before outlining the nuanced considerations needed when designing solidarity-focused zineing methods. It highlights reflections on the workshop space as a *site* for solidarity, the validation of experiences that others may not make sense of or relate to, and the ways in which the space of collaboration allowed for the participants to express their experiences in ways that they hadn't been given the opportunity to before. The chapter uses these reflections and draws upon interview data and creative zine artwork to sketch a hopeful future that arises out of spaces such as these, and highlights how these process-focused artful spaces can foster a better hope for the future of Tourette Syndrome.

Finally, the conclusive Chapter 7 then offers a cross-cutting of key themes arising throughout the analysis, providing conclusions and suggestions moving forwards. This chapter summarises the key arguments and concepts raised previously in the thesis, and asks questions of what public space *could*, and *should* look like. To do so, it draws upon the data and analysis that precedes this chapter to offer recommendations and suggestions for future research directions. It then moves on to consider some of the implications that go beyond the specific case of Tourette Syndrome, thinking back to some of the initial concerns and confusions I had when choosing to research Tourette Syndrome as far back as at MA level, and asks how this research can respond to these concerns now. A core part of this includes thinking about the wider geographical relevance of this research, and how this might contribute to the discipline more broadly speaking.

With this summary in mind, once more, Hall & Wilton (2017) call for greater attention to be paid to the diversity of embodied experiences that contest the disabled-nondisabled binary. Again, Tourette Syndrome is an incredibly varied disability in not only manifestation but also in how it is experienced. There is no binary in question here. Comparisons are not made between 'abled' and 'disabled', but rather the focus here is on representing Tourettic adults themselves. This thesis is for Tourettic people. I hope that some kind of representation can be found here for you.

## Chapter 2.2. Geography, Public Space, and Disability – A Literature Review

This literature review begins with an inquiry into public space, considering non-representational theory and post-phenomenological approaches to the [disabled] body. It then addresses some of the queer and crip interventions into public space, the body and disability. In doing so, it situates the research to follow in crip and critical disability studies, highlighting the ways in which crip approaches to geography are beneficial to the study of Tourette Syndrome and public space in the avenues for further, more nuanced, crip-geographical discussion of Tourette Syndrome that might arise.

Of particular relevance in the case of this literature review is public space, which underwrites this thesis. Public space as a topic of inquiry has a plethora of debate surrounding attempts to define it. These attempts include those that seek to disrupt the meanings of what ‘public space’ is assumed to be. Some longstanding definitions of public space such as shared space (Goheen, 1998; Hamilton-Baillie, 2008); *gathering space* (Amin, 2008; Kohn, 2004); free, *unticketed space* (Polletta & Kretschmer, 2013; von Hirsch & Shearing, 2000); and *sites of contact* (Jacobs, 2016) – to name a few- do exist, and have significantly informed and inspired these disruptions of publicity and public space. Normatively, the public sphere and public spaces generally are where the public is organized and imagined, as such (Young, 2011). We see that notions of shared, gathering, free-to-access, contact-rich public space(s) have been disrupted, developed and critiqued by geographers via non-representational theory (Thrift, 2008); post-phenomenological approaches (Ash & Simpson, 2016); feminist geographies (Mohammad, 2016); queer geographies (Valentine, 2002); and crip studies (Pritchard, 2020; Santos & Santos, 2018). For years now, debate over definitions of public space and where to even start regarding our inquiry into it have been asked. In his introductory paper, Don Mitchell sums this up succinctly:

*“So what now is public space? Is it simply nostalgia or utopia? Is it at all attainable as an ideal, or does it come to us already compromised by the working of power, the economy, the government? Or do those questions presume too much? Can we – and do we – satisfy ourselves with the ambiguity that public space necessarily is?”* (Mitchell, 1996: 128).

As the paper goes on to explore, there were multiple forms of disruptive thought influencing thinking on public spaces – various disruptive forces were beginning to take effect and have influence, and have continued to do so to this day. I initially here wish to acknowledge the vast array of published literature surrounding public space, thematically. For the purpose of this chapter, however, I wish to unpack ideas surrounding specifically non-representational theory, post-phenomenology, queer geographies, and crip studies in order to contextualise the discussions to come later in the thesis. Ultimately, this chapter aims to highlight the disruptions to inquiry into public spaces that have had particular influence over the design and analysis of this thesis.

## **2.1 The Geographies of Disability**

The Geographies of Disability could be considered an interdisciplinary sub-discipline of human geography which is closely linked with the development of a broader disability studies, and pays attention to the interconnectedness of space, social structure, culture, and the experiences of disabled, neurodivergent and chronically ill people, which has developed from a broader geographies of health (Gleeson, 1999). In the words of Curtis & Rivera, “Geographical research on human health and diseases is concerned with the processes and relationships in space and time that govern human interactions with their environment and with each other, in complex and ‘non-linear’ ways” (2010: 217). This could be in a variety of ways, including but not limited to considerations of climate change and globally contrasting geographies of health and wellness, the relational Geographies of Disability, hate crime and belonging in urban city spaces (Hall & Bates, 2019), or intersectional approaches within COVID-19 discourse regarding the production of anti-oppressive research outcomes, more generally speaking (Eaves & Al-Hindi, 2020). From health geographies, emerged a focus on disability, with the Geographies of Disability being summed up with clarity by Edwards & Maxwell:

*“Writers in the subdiscipline of geographies of disability have sought to challenge medicalized, paternalistic understandings of disability, by recognizing disability as an embodied experience co-produced in and through space at the confluence of individual experiences of impairment, and social relations and attitudes” (2023: 160).*

Examples of this might be in the discussion of embodied experiences of disability in relation to technological advancements and *distributory justice* (Dyck, 2016), the inquiry

into the experiences of a carer of disabled children with a focus on the politics and power dynamics present in the mother-disabled child relationship (Morrison, 2022) or even perhaps in the consideration of the implications of deinstitutionalisation of physically disabled and mentally unwell people in relation to social attitudes and a politics of care (Hall & Kearns, 2001). Notably, Edwards & Maxwell (2023) express a need to move beyond the dichotomies of public/private spaces in relation to the Geographies of Disability, and this is directly relevant as a call within the geographies of disability that speaks directly to this PhD research project. The emergence of the Geographies of Disability is closely tied to the broader development of disability studies. Whilst both shared a commitment to the dismantling of ableism (Linton, 1998; Imri, 1996), disability studies in particular paid attention to models of disability, and emerged in particular from the disability rights movements in both the US and the UK.

A geographical approach, taken in the Geographies of Disability, highlighted an important shift towards Non-Representational Theory (NRT) approaches that was very much in line with Human Geography as a whole, and I'd argue that this has continued. We see this in both Naughton's (2022) attempts to include the *neuro* in our NRT approaches to disability and space, as well as in Porkertová's (2025) work that highlights the ways in which the work on visual disabilities needs to engage with NRT to a greater extent in order to move beyond the idea of embodied experience as something that can be represented as fixed. With NRT highlighting the importance of *practice*, my approach responds to the oftentimes poorly accounted for differences in bodies and minds in NRT. The minimal existing research conducted in geographical ways into Tourette Syndrome necessitates this combined approach, which is something that has been done more broadly speaking in relation to critical disability studies as a discipline which has asked questions to unpack concepts such as able-bodiedness in ways that geographers haven't done to the same extent. In Hall & Wilton's (2016) paper, they write of how they "have deliberately focused attention in this paper on the ways in which NRT's emphasis on the immanent materiality of social life – the 'doings' of bodies in relation with other bodies, objects and space – offers provocative ways of thinking through disabled and non-disabled becoming. At the same time, we are conscious of the limits and shortcomings of this approach" (p739). It is in part these shortcomings that inspire the multiply inspired representational and NRT approaches to this research,

particularly regarding methodological approaches which will be elaborated upon in Chapter 3.

With this in mind, the geographies of disability offer a useful starting point but demonstrate that a departure from sole location of this research within this geographical sub-discipline is needed in order to move conversations further forwards. In much research surrounding disability, we are urged in the direction of the medical model of disability with a focus on the body as something that *has* a lacking, or a disability, or a mutation as a few examples (Oliver, 1990). This would then cause a focus on how we can alter or repair said bodies in an attempt to allow them full access into public spaces (Koegel *et al.*, 2001; Vellutino *et al.*, 1996; Williams *et al.*, 2008). However, an alternative approach would acknowledge the role of the non-human, encouraging us to implement the social model of disability, whereby people are *disabled by society* (Oliver, 1990). This changes the approach to public space and the study of access because there would be a greater question of ways in which we can alter society and the public spaces themselves in order to allow disabled people full access. A phenomenological approach aligns with this, but the post-phenomenological approach to disability provides a significantly more sophisticated social model of disability and potentially even beyond this.

Within research into disability, there are two particularly well-referenced models of disability. The first, being the *medical model*. This is the notion that disabilities are *things* that people *have*. This often results in person-first language, such as “person with a disability”, and conceptualised individual disabled bodies as a problem to be solved through medical approaches. The social model of disability however moves beyond this, and considers societal barriers, empowerment and inclusion as key (Oliver, 1990). The social model of disability has been influential in how it has shaped geographical research into disability. Given geography’s disciplinary interest and application of a *spatial* lens, inquiring into spatial aspects of disability offered many opportunities for further geographical engagement with disability beyond public health, whether in considering socio-spatial interactions between disabled bodies and the spaces that disable them (Freund, 2001) or in the geographical practice of advocating for changes in spatial design and policy briefing (Zajadacz, 2015), amongst many other notable examples of equal variety in application of the model (Chouinard, 2009; Kitchin & Wilton, 2000; Smith, 1999).

In particular, as geography as a discipline began to attempt to be *enabling* in their approach, (Gleeson, 2000) outlines how an “enabling geography presumes a social model approach [to disability]” (p65).

There are, however, many criticisms that have been made in relation to the social model of disability. Whilst Riddle (2020) argues that rather than revisiting the social model of disability, “our concern should be on how we conceptualize the notions of equality and justice to inform sound policy, and not on how we model the experience of disability” (p1509), others question the need for such a binary approach to disability (Gabel & Peters, 2004; Morrison, 2022). Oliver himself has acknowledged these in a follow-up paper that revisits the ideas behind the social model of disability 30 years after the original publication of the idea (Oliver, 2013). Ultimately, Oliver writes that “despite the impact this model has had, all we now seem to do is talk about it” (p1024). He states that emphasising impairment and difference was intended to protect disabled people and the services they engage with and rely on. However, cuts to funding of these services are being made based on a binary being made between most and least impaired. The context that we exist in today, even a decade on from Oliver’s revisiting of the social model of disability, is not the same and perhaps is not one in which the social model is the most applicable in comparison to the context of specific cuts to disability service provision and governmental decision making within which the social model of disability was coined. Since the inception of this term, the UK has seen constitutional reforms by the Labour government, a shift from a Labour to a Conservative-led government (and back again), and over a decade of Tory austerity measures amongst others. The political landscape in which we exist today is significantly different to that of 1990 when Oliver first wrote of the social model of disability. With this in mind, taking into account non-representational theory, post-phenomenology and the ways in which they disrupt these models of disability is vital to give context to the forthcoming research.

## **2.2 Non-Representational Theory, Post-Phenomenology, and the Disruption of Disability Models**

The non-representational approach is concerned with the processes of subjectivation – the process of becoming – rather than the subject or the object itself (Thrift, 2008). Coming from a British Geography context, non-representational theory considered the way that all of life is based on movement, and so we shouldn’t take a static

approach to the bodies we find within it. After all, if bodies are objectively not static, and especially so for bodies that tic as Touretic bodies do, then it makes sense to start with non-representational approaches to the body, public space, and Tourette Syndrome more broadly speaking. As Boyd states, “non-representational geographers think very differently about the human subject. For us, the human subject is distributed across space-time, constantly in the process of entering into, and departing from, temporally unstable relations between a multitude of actors and actants, all of which are doing the same” (Boyd, 2017: 29). Our bodies are not fixed or *set in stone*, but rather they continue to *become* through interaction with non-human actants also. One key concept within non-representational theory is *joint action*. Thrift (2008) describes what he terms *material schematism*, which ultimately says that people and things are brought together through processes of encounter. The two key features of joint action are (a) the question of intention, and (b) it’s dialogic nature. There is a question of intention when it comes to joint action as it can be argued that the outcomes of encounter cannot be fully anticipated by either of the entities involved. There is no clear intent, but rather an assemblage that has a technicity that propels it in a given direction: when something moves, it moves *with* or *in relation* to other things.

Regarding the dialogic nature of joint action, “encounters take place at the surface of things, and it is through encounters that space is transmuted into context” (Boyd, 2017: 31). All of this is to say, encounter is vital in terms of place-making and the bodily navigation and experiences of spaces more generally speaking. Encounter, as a term, can be considered as the body-to-body, tactile meeting between differing forces. The encounter is not an *empty* way of meeting and is significantly subject to affect and context (Wilson, 2017). Further to this, Wilson and Darling write that “encounters are centrally about the maintenance, production and reworking of difference; that encounters fundamentally frame urban experiences and subjectivities; that encounters produce and encompass multiple temporal registers; and that encounters offer points of possible transformation and opening to change” (2016: 2). *Encounter* is a key concept that has a significant impact on the way that spaces and places are experienced; encounters are the driving forces behind change and the re-imagining of spaces. Ahmed writes that difference is something emerging from encounters and so cannot be described as fixed (Ahmed, 2000). These encounters are not fixed, and this non-representational approach

to encounters is key for the arguments made in this thesis, particularly surrounding Chapter 4. Chapter 4 focuses on the concept of the *chance encounter* which is a concept employed across various disciplines. Bennett refers to the chance encounter as something that is not necessarily spectacular, and therefore inclusive of mundane everyday experiences (cf. Bennett, 2001), whilst Hens considers chance encounters from a bioethical standpoint, whereby healthcare interventions may shift the ways in which people experience the world, in how they alter the chances for encounters that may occur and impact on somebody's identity as they progress through life (Hens, 2022). The wider ~~significants~~ ~~significancet~~ of the chance encounter here is in its relationship to social difference. Social difference and othering are not fixed, and these processes can happen in a multitude of ways, many of which are particularly distinct in the case of Tourette Syndrome. In the context of this thesis, the chance encounter differs as a subset of encounters in that it specifically refers to encounters that may or may not happen, and that are partly a product of *impulse* and chance in the context of the Tourettic body and the limited control a Tourettic person may have over it. This is relevant in justifying the in-depth analysis required to unpick these when considering Tourettic embodied experiences of public spaces.

Additionally, Macpherson writes that “our physical body and sensations are understood to be on the move, interconnected with other bodies and contexts. This means our embodiment is dependent on how our body is put to use.” (Macpherson, 2010: 4). This develops ideas of non-representational concepts of joint action, and our bodies are in a constant state of becoming. This means that our identities and experiences are inherently shaped by the technologies and often contrasting contexts that we might find our bodies in. This is particularly so given how our bodies are so fundamentally object-oriented, intrinsically linked with the built environment, items or objects we use to navigate the world we live in, and so on (Thrift, 2004). Our bodies are *put to use* in different ways depending on the contexts in which we find ourselves in, which regarding public space tells us that the consideration of non-human elements of public space are incredibly important in understanding the ways that these spaces *use* our bodies. If our bodies are in this constant state of becoming, and if it is also influenced so significantly by the non-corporeal aspects of the spaces we find ourselves in, this is transformational

for how we should be approaching inquiry into the body and public spaces. This would lead us to consider a more post-phenomenological approach to our inquiry.

Phenomenological trains of thought have contributed to a movement past a Cartesian approach to the world – meaning that inquiry should be based on logic and reason, with no consideration of the emotional lest it distract us from the actual meaning of the world (Feuer, 1963; Morgan, 2018). This therefore enabled the consideration of emotion, acknowledging that emotion is at the very core of our lived experience (Bondi, 2016). It is important to acknowledge that these considerations have come about in conversation with feminism, postcolonialism, and indigenous thought. At the most basic level, phenomenology says that the meanings of the world, as such, only come into existence in relationship with our own senses, emotions and consciousness (Ash & Simpson, 2016) and this is why we must move away from the Cartesian approach in inquiring about the world. On the whole, the starting point for phenomenology is the lived experience of human consciousness. Husserl, who is referred to as a pure phenomenologist, posed the idea that consciousness is always conscious of something, and therefore we could say that in phenomenology the world is the sum-total of objects that can be known through experience (Harris, 1995). However, scholars such as Heidegger, Hegel, and Merleau-Ponty took a more existential phenomenological approach, also referred to as existentialism. In short, this consists of being more interested in *concrete* human existence. Using Husserl's ideas of consciousness as a starting point, existentialists such as Merleau-Ponty emphasized that consciousness is always an embodied consciousness: "I no longer pay attention to my body, to time, or to the world such as I live them in pre-predicative knowledge, that is, in the inner communication that I have with them" (Merleau-Ponty, 1962: 74). In this instance, the communication that Merleau-Ponty talks of is something that occurs consciously and by choice. Merleau-Ponty here attempts to consider the pre-subjective self, moving beyond bodily responses.

Most simply put, post-phenomenology attempts to combat the limits of subjectivism that can be found within phenomenological trains of thought. Post-phenomenology can be described as a modified phenomenology that considers both objectivity and subjectivity within its inquiry into the world (Ash, 2020a). This means that it considers not only the consciousness discussed by classical phenomenologists, but

also ideas of pre-conscious experience. Discussing the unthought realm of the everyday (cf. Seamon, 1980), Ash and Simpson outline a post-phenomenological approach that considers those experiences that the body has within spaces that occur prior to the moment in which any conscious cognition or reflection is able to happen (Ash & Simpson, 2016). This means that assigning meaning to an experience occurs somewhat pre-consciously, but still in relational ways as outlined by previous non-representational approaches. By acknowledging those experiences of the world that do not necessarily occur through thoughtful reflection but rather in a more immediate way that is almost instinctive or impulsive, post-phenomenological approaches consider the role of the non-human and the human, questioning phenomenological arguments of a subject-object divide (Ash & Simpson, 2016; Lea, 2009).

With this in mind, James Ash (2020b) in particular outlines how a post-phenomenological approach helps to define space as a “dual process of differentiation and distancing that produces different modes of nearness and farness...” (p181). In short, Ash is here acknowledging the importance of feelings of closeness or farness from other affective bodies (human or non-human). A part of this is feelings of belonging (as will be explored in Chapter 5), but also could be applied to differing bodyminds, by which I mean to say the *othering* of disabled folks...

In summary, a non-representational approach focuses on becoming, and not on the static act of ‘being’. It emphasises movement and the dynamic nature of bodies. It is crucial in ensuring that we are able to consider the processes of place making and sense-of-place in nuanced ways. This approach highlights the ways in which considering the concept of encounters is significant, precisely because of the relational nature of the ways in which we experience spaces and places as human and as affective beings. In thinking through the relational nature of experiences and encounters in a post-phenomenological way, we can better inquire about the fluid and changing nature of disability. Tourette Syndrome is a condition that waxes and wanes, this being a part of its very description (NHS, 2024), and so this is particularly important to consider when inquiring into the embodied experiences of public space had by Tourettic people. A post-phenomenological approach also explores that feelings of farness and nearness in affective spaces, and how they might influence a sense of belonging amongst disabled people. By considering the relational, ever-changing approach of non-representational

theory and post-phenomenology, questions surrounding sense-of-belonging are brought to the surface within our inquiry into Tourette Syndrome. It provides a comprehensive and nuanced framework for understanding disability and public space(s), and proves foundational in influencing this research throughout the thesis.

With the post-phenomenological approach to the body taking such interest in processes of subjectivation, this is a significant difference as it would, on the whole, argue that the body and non-body are equally as vital to consider when thinking about space (Grosz, 1998). In terms of activism, once more, the social model of disability has been praised in holding society to account, but it is important to recognize that it has been critiqued within the social sciences. Taking a NRT approach to deaf tourism studies, (Jensen *et al.*, 2023) outline the ways that many papers in the field embrace a social model of disability but continue to view disabled people as a homogenous group. Additionally, considering Hannah Arendt's ideas of plurality (Arendt, 2003), I acknowledge the inherent diversity of the human body. With this in mind, we are pushed in the direction of the post-phenomenological consideration of both oppressive powers of society and the physical materialities of human difference and [dis]ability. And so, it can be argued that post-phenomenological disruption of inquiry into public spaces in relation to the disabled affective body demands something alternative, something that moves past the social model of disability. Owens (2015) suggests perhaps there is confusion, and a general *lacking*, with the social model of disability because of the use of the term *model*. She refers to it as confusing due to the simultaneous development of differing definitions of it, as well as stating that there is potential for it to be developed into a workable and usable model. Moving on with this post-phenomenological approach to the study of public space and the disabled body, in this instance Grosz argues that the body is a social artefact whereby the built environment provides the context for bodies across the globe – the body acts as a site for space to inscribe meanings upon it (Grosz, 1998). The city, Grosz argues, provides a sense of order that creates networks resulting in links between otherwise unrelated bodies, using the comparative example of a banker and somebody she describes as homeless. Generally, Grosz leans towards a post-phenomenological approach to space and the body, in stating that the “city [as an example of a public space] is a reflection, projections, or product of bodies... a product not simply of the muscles and energy of the body, but the conceptual and reflective possibilities of consciousness

itself” (1998: 44-45), going on to question why it is that we often assume the body to be a machine that is controlled by consciousness, and consciousness exclusively – they acknowledge here the inherent diversity of the human body (cf. Arendt, 2003). Grosz argues that there is a problematic dichotomy that exists in academic texts surrounding space and the body when writing that oppositional pairs such as mind-body; passion-sensibility; temporality-spatiality (and so on) neglect to allow the consideration of the body as a cultural product, which is an inherently post-phenomenological way of approaching the topic at hand – something that, as established, is important in inquiry into the body and public space.

In the case of Tourette Syndrome, again, post-phenomenology allows us to consider impulsivity and tics, and post-phenomenology’s applicability to research into public spaces proves valuable for this project. However, to return to my earlier point, non-representational theory and post-phenomenology have not adequately engaged in bodily difference, and in disability in particular. A de-centring of the body and focus on subjectivity amongst both do not allow for the addressing of specific material and embodied differences. Discussions are had over the ways in which these bodies might affectively contribute to placemaking, as one example, but only seem to do so in more abstract and disembodied ways. Whilst non-representational theory and post-phenomenology play a key role in conceptualising and contextualising the research in this thesis, as significantly as influencing the very models of disability that this thesis acknowledged, it is important to consider this limitation and to highlight the importance of moving beyond the boundaries of these concepts. In order to address this, it is key to consider queer and crip approaches to bodies and space that are relevant here. Non-representational and post-phenomenological approaches have opened up new queer and crip avenues for inquiry into public spaces, which have further influenced this research. NRT, post-phenomenology, and various models of disability offer a foundation upon which to build on here.

### **2.3 Queering Public Space**

When considering the influence of queer studies and queer theory within geographical inquiry into public spaces and bodies, we must initially stress that here the term *queer* is not used solely in a way that is synonymous with LGBTQ+. Rather, it is a mode of thinking that challenges assumptions that are taken for granted, oftentimes – but

not exclusively – regarding gender, sex and sexuality (Browne, 2009). Butler (Butler, 1990) challenged gender identity and normative masculinities/femininities, accusing heterosexuality itself of being performative, stuck in a highly rigid and regulated frame. In the use of the term *performative* here, Butler is arguing that heterosexuality is something performed based on societal norms and expectations, which reinforces the ideas of binary gender and of what is considered the *norm* in society. Butler challenges notions of heteronormativity which is something that results in the *othering* of non-heterosexualities. Butler wrote extensively from a queer perspective (cf. Butler, 1990, 1993), and alongside other key voices (Binnie, 1996; Sedgwick, 1996; Valentine, 2002) they assisted in the destabilization of normativities that *other* queer folks and contribute to a limited sense of belonging in spaces and communities. Queer theory, put simply, has resulted in us questioning ideas of normality. It questions our assumptions of not only sexuality, but of race, age, class, disability and causes us to be critically considerate of our assumptions as researchers. Sexuality is a hugely diverse set of lived experiences and so its consideration has led to these newer, *queer* ways of thinking about difference, particularly in the ways in which it ultimately raises the question of whether the notion of fixed sexual identity is either desirable or tenable (Brown & Knopp, 2003). These have arguably had significant influence on approaches to the study of public spaces within human geography.

Work on public spaces by Hubbard (Hubbard, 2001) outlines that within public spaces generally, those whose sexualities or sexual activities are deemed risky, dangerous and/or or desirable – or those associated with them – face various rules and regulations that may alter their rights as citizens who access public spaces. Hubbard discusses the moral panic associated with the HIV/AIDS epidemic in this specific article, considering how as a result all LGBTQ+ existence or even association with LGBTQ+ people was considered risky and therefore undesirable – even sometimes anti-reproductive (cf. Renkin, 2009). Renkin also covers how many queer people are considered the *Other* within a specified nation, due to the fact “[f]or nationalism, the proper member of the nation is both heterosexual and reproductive” (p23) with LGBTQ+ people seen as neither. This would make LGBTQ+ people undesirable, in line with Hubbard’s (2001) work. Moving further, Hubbard refers to cases whereby cities may have *good* gay tourism services, such as gay bars and gay clubs. However, it’s considered that despite the presence of these

queer pockets within a wider space, it is *for* visitors and so the sense of queer citizenship is still absent. In the context of Hungarian right-wing attacks on LGBTQ+ people during Gay Pride marches, Renkin writes that “rather than being merely objects of innate hatreds... it is also the concrete activist practices of LGBT people that have placed them at the centre of postsocialist struggles over belonging and right-wing anger” (2009: 22), going on to argue that this is a result of things such as Gay Pride marches. However, drawing upon Hubbard’s (2001) insights once more, he states that as a result of simply the lack of citizenship amongst LGBTQ+ people, the simple act of *being* a member of that community in these supposedly public spaces is something to be considered a political act itself. This evidently largely shifts our perspective as academics interested in public spaces. Despite this queer analysis, Hubbard himself states limitations of his analysis by stating that “a more fluid and topologically complex interpretation of public space... is necessary to understand the changing geographies of sexuality” (Hubbard, 2001: 52). He acknowledges here that we need a queer approach to inquiry into public space(s) in order to allow its enquiry to *keep up* with the inherently queer nature of the geographies of sexuality.

Queer studies largely frames bodies themselves as political, whether that is through the emotional, political activism of the queer body during protests and marches (Johnston & Waitt, 2015) or as bodies which have significant impact over the production of spatial identity in terms of providing *safe* spaces within the public realm (Valentine, 2002). Ideas of belonging have been explored not only by Hubbard (2001), but by Fenster (2005) amongst others (Beebeejaun, 2009, 2017; Rosenberg, 2017; Smets, 2013) – ideas of belonging being particularly relevant in the context of this thesis. However, Fenster (2005) begins to move past the formal structures of belonging and citizenship discourse, in their consideration of gendered belonging, the impact of memory, and consideration of immigrant and indigenous gendered belonging. Beginning to consider other bodies in their queer approach, Fenster draws some interesting links between queer studies, indigenous studies, and other means of considering notions of belonging, exclusion and *claim* over public spaces and spheres. They question capitalist able-bodied ideals and desires for the public spaces in question, such as *efficiency*. Alongside this, Leanne Simpson, a key thinker in inquiry into indigenous resurgence, discusses how indigenous approaches to space and land can be considered queer, in the sense that what may seem

like *dead* or *useless* land to urban capitalists may be of use still, from an indigenous perspective (Simpson, 2016, 2017). For example, you may not be able to fish in a river due to excessive pollution, but you can still kayak across it, and so you can be in relation to place in alternative ways. Just because the land is *sick* does not mean that we should abandon it. Asking questions of this type may urge us to ask not only what spaces are *useful* and/or *valuable*, but the bodies that are too. This bodywork that Queer Theory has contributed to has significantly influenced the inception of Crip Theory, and leads us to consider not only queer bodies in terms of sexuality and gender, but also queer as inclusive of disabled, neurodivergent, and chronically ill bodies. It is the queering of public spaces that move us towards the crippling of the body, as such.

#### **2.4 Crippling Bodies in Public Space**

A natural follow up for queer research approaches is crip. Considering the aforementioned queer inquisitions into the public sphere and the body have occurred alongside crip studies - which can be considered inherently queer by nature - leads us to this point. The concept of crippling means to apply a disability justice lens to the *thing* which you are trying to crip. Practically this might mean applying an anti-capitalist politic; intersectional consideration; recognizing wholeness and humanity; and collective access and liberation, to name just a few principles (Sins Invalid, 2015), and could be considered a clear intellectual development that has arisen through queering. A queer-crip alliance has been forming and strengthening for many years, through collaborative activism and scholarly inquiry. There are obvious shared experiences that occur between the disabled and the queer communities, from generic oppression due to being *different* (García-Santesmases Fernández *et al.*, 2017), to the specifics of familiar isolation, whereby these populations often find themselves growing up in environments where nobody shares their experiences (Sherry, 2004). However, we also see key moments in history where these two individual communities worked together. Such as in the sit-ins of 1972 by disabled people who were demanding the signing of Section 504 in order to allow them equal rights in the USA. The owners and customers of a nearby lesbian bar came to wash their hair as their carers were absent (Bateman *et al.*, 2020; Holmes, 2006; Lebrecht & Newnham, 2020). It is therefore only natural that queer and crip studies have a huge influence and impact upon one another, both regarding activism and regarding academic inquiry.

Similarly to queer theory, critical disability scholars who engage in crip approaches to research tend to take a post-phenomenological approach to the body and this can be seen notably in relation to ideas of belonging and difference:

*Critical disability studies “understands disability as a construct that aids in upholding existing power relations and systems. At the same time, it emphasizes the importance of embodiment, lived experience, and relations from the micro (within bodyminds or between bodyminds) to the macro (institutions, cities, systems) level. Most theories of CDS take a both/and approach to embodied and theoretical knowledge.”*

(Price, 2024: 19).

The direct reference to lived experience here is in line with a post-phenomenological approach to the body, in that the lived experience being referred to concerns a range of scales and ways of knowing (both body and mind – bodyminds). If considering the body alludes to the corporeal interactions with spaces and places that the body has, considering the mind also refers to the conscious and pre-conscious interactions. The approach of bodyminds connects strongly with post-phenomenological frameworks.

Thinking back to the limitations of the social model of disability, a crip approach encourages us to think towards affirmation models of disability. Non-representational theory alone is not enough to lead us towards this affirmation model of disability, but through tracing approaches to the body through queer and crip theory, we end up at this more-than-social model moment in the literature. Rather than the typical social model explanation of society as something that disables individual people, an affirmation model looks towards creative positive collective social identities for disabled people (Swain & French, 2000), which relates to Price’s discussions here of interactions between bodyminds also in the ways that she discusses creating a collective approach to accessibility rather than an individual one. The interactions between disabled bodyminds are important and are a part of creating accessible academic spaces in her book (2024).

Similarly to within queer discourse, hate crime and fear has been considered a great amount within disability discourse (cf. Burch, 2022; Chakraborti & Garland, 2012; Hall & Bates, 2019; Hughes, 2020; Johnson & West, 2022; Schalk & Powell, 2008). In attempting to theorise the reasons for hate crime, criminologists Chakkraborti and Garland state that “[i]t is not someone’s identity per se which makes them vulnerable in the eyes of the perpetrator, but rather the ways in which that identity intersects with other aspect of their

self and situational factors and context” (Chakraborti & Garland, 2012: 510). That is to say that *bodily difference* alone is not to *blame*, as such, for becoming targets of this category of abuse but rather are simply one piece of the post-phenomenological puzzle, metaphorically ~~speaking~~speaking. Alongside Hall and Bates (Hall & Bates, 2019), they attempt to shift hate crime discourse away from a focus on, in this instance, the disabled person and towards a greater emphasis on socio-spatial context within which the hate crime can occur. Once more, this lines up with an approach that aligns with affirmation model of disability.

Crip theory has made significant contributions already to geography as a discipline and more specifically in many sub-interests within the discipline. Crip theory has been applied to the geographies of masculinity by the likes of Gahman (2017) who discusses how men in rural Southeast Kansas, USA had often referred to their bodies as ‘weapons’, ‘tools’ and ‘machines’ in suggesting that masculinity is intrinsically linked with productivity, and the ways that this reinforces false ideas of disabled people’s lesser capabilities of working. In doing so, Gahman focuses on crippling the geographies of masculinity to spot ways in which different geographies are considered through an intersectional lens. Similarly, Inckle (2014) takes a ‘crip ethos’ of considering disabled embodiment as a radical challenge to normativity in gender politics. Notably, Inckle concludes that “the profoundness of (my) disability [... creates] a politics of hope and humanity” (p399). In doing it also encourages intersectional consideration of the crip into the geographical. Once more, to *crip* is to apply a disability justice lens, and this has been the common objective of these two papers in considering intersectionality in their disability work. It is also interesting to note some specific geographical research happening currently that concerns the relationship between disability and time. Whilst criptime is a common concept in critical disability studies (cf. Katzman *et al.*, 2020; Koppers, 2014; Samuels, 2017; Sheppard, 2020), Eva Kašparová of Masaryk University is researching how time and disability intersect in everyday situations and publics, with the acknowledgement of geographies primary focus on crippling spaces and places, rather than considering ‘crip temporalities’ (Kašparová, 2024). This work has not been published as of yet, but it is promising to hear of the work happening to further crip different geographical concepts, such as temporality, that are happening as I write this.

Furthermore, this crippling of public space also extends into digital spaces. Social media sites have previously been conceptualised as publics by scholars (cf. Tierney, 2013; van Dijck & Poell, 2015), and Christensen-Strynø (Christensen-Strynø, 2020) has argued that whilst social media platforms are capitalist in that they seek to accelerate productivity, social media – in this instance, Instagram – can offer hope and potential for facilitating new forms of crip, temporal communities that span time and space. Outside of the specific discipline of geography, crip scholars are working in particularly geographical ways around this topic. Notably, Pal (2019) writes on Twitter (now X) activists and the nuanced complexities of navigating activist spaces that are digital and therefore contested, being referred to as *slacktivism* by many. Pal is particularly engaged with Warner’s theory of publics and builds on this by highlighting the ways that crip activist communities on twitter generate affective networks, whilst considering the complexities of the construction and reconstruction of crip digital ‘publics’. In particular, Pal asks the question of ‘what is possible for the disabled protester?’, whilst taking a geographical approach to analysis. By this, I mean to say that Pal’s work is particularly interested in the digital network and community building that happens, in a spatial way. Community, mobility, and *place* have been discussed in these digital contexts, and are all influenced by embodiment. The work on embodiment and embodied experiences of public spaces in physical *spaces* extends far beyond the physical and is applicable in these digital contexts too – as outlined by the aforementioned work of Christensen-Strynø (2020) and Pal (2019). However, connections between the two have not necessarily been made in more direct ways.

## **2.5 Concluding thoughts**

Non-representational theory and post-phenomenological thought have been instrumental to the conception of this research project. Whether in the idea of our bodies being *put to use* in non-representational theory, or the post-phenomenological approach to the body that highlights an affirmation model of disability. Additionally so, whether in the queering of public spaces in rethinking their use (in conversation with indigenous theory) or the crippling of normative ideals of bodyminds. NRT and post-phenomenology lack an appropriate consideration of bodily difference, and these are the approaches that appear to have been most commonly adopted within the existing literature surrounding the geographies of disability. Once more, the geographies of disability offer a useful

starting point for this research, but highlights the need for a departure from solely the sub-discipline in order to make important contributions and conduct nuanced, contextually informed research regarding Tourette Syndrome specifically. Similarly, the social model of disability lacks a bodily awareness. This project attempts to find routes forwards. This previous scholarship has inspired this project significantly, and this chapter has offered a summary of the key concepts and literature to consider moving forwards into discussions to follow about this research's methodological design, analysis, discussions, and conclusions. The literature outlined here leads to the highlighting of how geography can greatly benefit from further crip intervention when it comes to the study of disability and public space (amongst others), and this is the disability justice and crip direction that this thesis takes the geographies of public space and disability. In doing so, it takes the gaps in literature and shortcomings of existing Tourette Syndrome research that NRT might raise, whilst taking an arguably representational approach to research methodology (as will be outlined in Chapter 3) – the lack of existing literature in this specific area necessitates the use of representational approaches in order to bring Tourette Syndrome research into the present and to *catch up* with the rest of the geographies of disability, so to speak. The research takes a crip and collaborative approach to the study of Tourette Syndrome and public space, and resultantly leads us in the direction of prioritising the consideration of Tourettic adults, and in providing research spaces for them to be involved in from the outset, rather than doing so with non-tourettic stakeholders in Tourette Syndrome (i.e. parents of Tourettic children). Through the crippling of non-representational theory and post-phenomenology, I here bring together an affirmational, non-tragic model of disability (and neurodiversity) that builds on the literature mentioned here. As this thesis will go on to highlight, the non-affirmation model of disability in the case of Tourette Syndrome values people as more than 'doomed to a sad life', and frames Tourettic people as key thinkers and knowledge producers in regards to Tourette Syndrome discourse. The analysis to follow in this thesis is underwritten by this approach, and resultantly takes a Tourettic-people-first approach to researching the embodied experiences of public spaces had by Tourettic adults.

### ADD-PLA Chapter 3. Methodology

The prior literature review demonstrated the significant need for experience-based consideration of adults with a diagnosis of Tourette Syndrome. Where Tourette Syndrome and experience has been explored it has largely considered those below the age of 18, which results in a lack of consideration of adults even beyond research, in healthcare and support settings. As summarised concisely by one of the project's participants:

*What we've noticed is that as adults, once you hit 18 you kind of disappear off the face of the earth when it comes to services and support*

- Lorna, Interview 1

What this project aimed to do was to consider the experiences of adults diagnosed with Tourette Syndrome, here defined as people who are of age 18 or above. Through doing so, it uncovers the embodied experiences that Touretic adults have in and around public spaces both in the physical and digital worlds, and furthermore seeks to consider embodied experiences of solidarity, community-building and isolation that arise from these accounts of publics. By taking this step, the hope is the furthering of inclusion of adults in Tourette-research and the application of findings for the purpose of applying for the funding for the facilitation of support for Touretic adults.

The chapter has been structured in a way that opens with some comments on the epistemological and ontological considerations made in the methodological planning of the research in order to contextualise the project. It then subsequently contextualises the project and gives specific justifications for, and reflections on, methodological choices made across the full scope of the research project that led to the mixed-methods approach, implementing a combination of in-person and online focus groups (n=2), interviews (n=38) and a zine-making workshop (n=1). The chapter offers elaboration on some distinct reflections and approaches that were made, [bearing](#) in mind my positionality as Touretic researcher, and considering the wider landscape of Tourette Syndrome discourse and how it impacted the project.

### **3.1 Contextualising the research**

As particularly outlined in Chapter 2, there is a plethora of Tourette Syndrome research that exists and that has been published in reputable journals. This section aims to address the need for this research, and highlights some of the distinct aspects and foci of the research project in order to provide broader context. It begins with specific research questions and [the more](#) broader aims of the project itself, before considering the ontological and epistemological approaches taken and justifies the need for both participatory-inspired research and more broadly social science-based research into Tourette Syndrome.

#### **3.1.1 Research Questions**

1. How is the Tourettic experience of public space distinct, and to what extent is Tourette Syndrome a barrier to using public spaces?
2. To what extent does social difference influence the Tourettic experience of publics, physically and online?
3. How can zine-based methods be used productively in researching the Tourettic experience of public space?
4. What can geographical consideration of a Tourettic point of view contribute in regards to...
  - a. Charitable organisations and their practices?
  - b. Healthcare professionals and their practices?

#### **3.1.2 TIC-Hull**

From the outset of this project's planning, TIC-Hull were a collaborative partner within the research. TIC (Tourette Syndrome Inclusion in the Community) is a regional charity in the Hull area, and provides support to "anyone affected by Tourettes Syndrome and tic disorders within Hull, Lincolnshire and Yorkshire" (Tourette Syndrome - Inclusion

in the Community, 2024). Kim Mitchell, CEO of TIC-Hull kindly provided the following statement for context about the charity's roots and original aims:

*“Upon receiving the diagnosis of Tourette Syndrome for my child, I was struck by the lack of support accessible to both my child and our family. Working within a healthcare environment accustomed me to receiving comprehensive training across various areas to enhance staff understanding of the conditions encountered daily. However, it was concerning to observe that medical professionals and educators exhibited minimal knowledge of a condition impacting approximately 1 in 100 school children. This realisation grew more disconcerting and our circumstances worsened and I encountered adults facing similar challenges. Establishing the charity aimed to unite a community, offering peer support, a secure refuge, and eventually educating individuals surrounding our children and adults, providing them with the necessary support throughout their lives. Every individual deserves a comparable quality of life, and through our organization, Tourettes Syndrome Inclusion in the Community (TIC), we strive to realise this aspiration.*

- Kim Mitchell, TIC-Hull – 6<sup>th</sup> March 2024

I came to meet Kim through a mutual friend, who I met through previous academic research. I developed a genuine friendship with them, and they knew of my hopes to pursue a PhD. Through their own engagement in community facilitation and TS-activism, they knew Kim. At the time, Kim was in the process of registering TIC-Hull as an officially recognised UK charity, and so we were introduced to each other. We both had the same hopes for TS research, and I was grateful to have been offered an opportunity to collaborate with the charity after mentioning that I was applying to a PhD programme.

The collaboration between myself and TIC-Hull was a central and important part of this research. The collaboration began in November of 2019, whereby I discussed with Kim Mitchell (TIC-Hull CEO) about my plans, and we began to collaborate on ideas for the research and the funding application. The working relationship extends beyond the case of this research, and collaboration on this research has persisted throughout the entire project. From the start of the PhD programme in October 2020, to the day of thesis submission in December 2024 (and beyond!), TIC-Hull and I have and will collaborate(d). On paper, our collaborative relationship took the form of me as researcher volunteering, engaging in Trustee committee roles, acting as keynote speaker in research conferences

arranged by TIC, and working to facilitate adult-specific services in collaboration with the other staff and volunteers. Furthermore, it was agreed that I would act as a representative of TIC-Hull in international conferences, such as the European Society for the Study of Tourette Syndrome (ESSTS conferences), amongst others. On TIC-Hull's end, they provided me with dedicated desk space for my research visits to Hull, resources for hosting any in-person research activities, providing me with additional funding for travel to and from TIC-Hull events, and facilitated networking with the Tourettic community beyond the charity, connecting me in particular with facilitators at Tourettes Scotland and other local community groups, and endorsed my research to their members. Together, we were able to determine what the adults in the Tourettic community needed and wanted from this research, and as a result we were able to carry out this research in a way that truly centred Tourettic adults themselves. However, our collaborative relationship was much more than what was officially outlined. I became deeply integrated within the community of service users. I made real and genuine friendships, and many of the participants whose stories are included in this thesis I now consider to be close friends of mine and to be people in which I find *solidarity* and *belonging* – two key themes that arise throughout the course of the analysis chapters within this thesis. This collaborative relationship resulted in me finding a sense of community and support that I had never experienced before, and this was something that was fundamental in allowing me to care for my mental wellbeing whilst carrying out this emotionally charged research in the stressful context of a PhD programme. The layers to the collaboration between myself and TIC, both as an organisation and a community, are particularly deep and underwrite the findings of this research.

### **3.1.3 Overall aims of the project**

With the aforementioned research questions in mind, it is important to address the ways in which they address the broader aims for the project. My intentions for this project were to collaborate with tourettic adults as much as possible within the scope of the PhD programme. As the literature review in Chapter 2 has outlined, adulthood experiences are often left out of the conversations in published Tourette Syndrome [work](#). A key motivation of mine for this project was addressing this. Additionally, when I began the project there was significantly limited literature that included tourettic people in terms of carrying out research. This is to say that whilst Tourettic people have been involved in some research

in an advisory capacity, collaboration including Tourettic people being involved in the research inception, data collection, analysis, and dissemination of findings seems to be missing. Over the last couple of years, there has been an increase in the inclusion of tourettic people in conducting academic research. Some of these are specific papers and research projects that I have been involved in directly also (cf. Conelea et al., 2022). However, there is still a significant limit to the amount of collaboration occurring between tourettic participants and the researchers in current Tourette Syndrome research. Filling the gap in literature including and collaborating with Tourettic people in participatory action research (PAR)-inspired ways was important to the ethos of the project from the [ethosbeginning](#).

It is important to acknowledge here that throughout this thesis I use the language of participatory-inspired approaches to research, rather than making the claim of this research being something I feel can be considered as an entirely PAR approach itself. This is because of the participatory limits of the approaches taken in this research, such as a lack of participatory approaches to all stages of the research, including research inception at the point of applying to funding and in the writing up and dissemination of the research findings. However, further to the project's aims regarding filling gaps in literature and collaborating with tourettic people, the project aimed to gather data surrounding the experiences and the needs of adults who are diagnosed with Tourette Syndrome. It aimed to do so in a way that findings could be put into an executive summary to be used by collaborative partner charity, TIC Hull, to assist in applying to funding for adult-based services. In acknowledging the limited extent of participatory approaches to research that can be taken within the context of the PhD programme (notably the slower pace, work to reduce power dynamics that are limited by the qualification I received through conducting this research, my receiving of a stipend for the work, and so on) working in a way that allows the collection of data and material more broadly speaking that can be used to apply for further funding is something that was incredibly important to this project. A key tenet of participatory research is the collaborative planning for the future beyond any smaller project timelines, and that *change* should be achieved in the context of these projects (Pain et al., 2019; Pain & Francis, 2003) . The intent to apply for further funding and allow TIC-Hull to use research reports from the project to assist in their fundraising was one way in which I could ensure longevity of this project and its aims in the context

of a time-restricted PhD programme. In this regard, I do not consider this work to be participatory action research, but rather inspired by approaches taken in more extensively participatory research.

As this thesis will continue to outline, service provision for adults is significantly lacking in not only a UK context, but a global context too. A key aim here was to be able to use some of the findings from this project to address this through helping to offer more services further down the line. On a similar note, having worked in community facilitation roles within the UK context for Tourette Syndrome for many years, the creation of services for adults and simply connecting Tourettic adults also was a personal goal I had for this research. There are implications and benefits of this that will be discussed in more depth during Chapter 7 in talking through collaborative zine making, but also this is something that has potential to come out of an increased amount of funding for adult services within the charity.

#### **3.1.4 Ontological & epistemological considerations**

With the ontological and epistemological approaches outlined in Chapter 2 in mind, conducting the project in a way that was as participatory as the PhD programme confines allowed for was important to me. Again, Tourettic people and our experiences are constantly being made and re-made; they are in flux. With this in mind, a participatory-inspired approach seems the most appropriate in order to ensure that I am not solely capturing a moment and portraying it as that person's entire experience. Though it was not possible to conduct multiple interviews with every single participant, it was important to me to ensure that I was staying in touch with all participants throughout the course of the project to ensure that there was always opportunity to update me about any changes or anything they felt that they wanted to add, remove, reword, and so on regarding their previous interviews and/or focus group contributions. Even in situations where participants couldn't give specific examples to highlight experiences that they had of public space and Tourette Syndrome, it was key to value the non-normative ways in which Tourette Syndrome and public space are experienced, in messy ways that are not always easily demonstratable or put into neat, thesis-ready quotations. In line with postmodernist acknowledgements of *mess* within experience-based research, this was also important for me. Whilst *neat* data might be easier to work with in that it might not contradict itself in some experiences being shared, and people might not change what

they wanted to say in interviews, I wanted to ensure that in line with being as participatory as possible that I didn't have a requirement for 'neat' or even 'fully formed ideas' by participants. I always prefaced interviews, focus groups and workshops with a statement or disclaimers similar to "I don't expect everything that you have to say to be profound or thesis-ready – half thoughts and ramblings are always welcome in these spaces". In doing so, I wanted to actively work to allow for mess. Part of this involved allowing participants to see transcripts before they were finalised to make sure things like their tics and specific wordings were representative of their experience and of their recollection of the interview. It also involved including participants in the designing of the project through hosting two advisory focus groups at the start of the research, prior to conducting any interviews, designing workshops, and so on.

This is all key to consider in conducting research into Tourette Syndrome. This thesis has already highlighted previous Tourette Syndrome research and considered the medicalised approaches to it. Participatory research into Tourette Syndrome, as far as I have been aware over the years, has not happened. The closest that I am familiar with at the time of writing is a recent project that included two tourettic researchers in the co-production of an animation about accessing TS services in the UK (Babbage et al., 2023, 2024). I was one of the researchers in this team, and though it included tourettic people through all stages, I do feel that it was not a participatory approach. It was shaped by tourettic people, yes, but not by participants themselves by any means. The approach I took to this thesis is, therefore, distinctly participatory-inspired. This is not to say that the project was as participatory as I would have liked it to be, as it is my argument that this is not possible within the scope of a time-restricted PhD programme in the UK context. However, the steps I have taken aim to be a step forwards in participatory approaches to Tourette Syndrome research. Participatory approaches to Tourette Syndrome research are needed for many reasons. What was key for me in the context of this research in particular was a sense of autonomy over the ways that tourettic people are being researched. I wanted people to have a say in this and ensure that they feel that they are able to feel represented in accurate ways – I wanted to ensure that participants had some kind of autonomy over the ways that I wrote about them in this thesis. Further to this, there is something in particular about this autonomy and involvement of participants in a participatory way that speaks to many of the tourettic community's concerns over the

infantilisation of Tourette Syndrome (Kushner, 1999). As we have explored, Tourette Syndrome is often referred to as a ‘children’s condition’ and there is an overwhelming focus on under-18s in research and other forms of representation. Within this project, I had the opportunity to push back against this by giving tourettic participants autonomy over important decisions regarding the ways that the project ran. Every participant is an expert by experience, and was treated so within this research project. With this, it was my hope to take an intentional step away from the infantilisation of Tourettic adults.

Additionally, it is important to acknowledge the rich history of stigmatised representation regarding Tourette Syndrome. This is not only by the popular media but also by academics and Tourette Syndrome researchers themselves. A notable recent example is the *witch hunt* of sorts that some researchers have set out on regarding the accusation of specific content creators who produce content to raise awareness about their experiences of Tourette Syndrome (Müller-Vahl *et al.*, 2021). This is as a result of recent stigmatised discourse surrounding the supposed ‘spread’ of tics through social media sites such as TikTok (Forsyth, 2021; Hull & Parnes, 2021; Kennedy, 2020; Olvera *et al.*, 2021; Zea Vera *et al.*, 2022). There is a significant focus that comes from clinical research papers and research situated within the medical sciences that Tourette Syndrome is an objectively negative thing, and the narrative portrayed is a desperation for ‘cure’ and eradication of Tourette Syndrome. A medicalised approach to disability views disability as the problem, however the social sciences are more likely to take a social model of disability approach. Whilst there is a pool of social science research that engages with Tourette Syndrome, it is significantly limited. Some of the current work particularly raises the need for social science approaches to Tourette Syndrome research. One way that social scientists have approached this in particular is in the acknowledgement of the ways in which we as Tourettic people cannot take movement *through* space for granted (Davis *et al.*, 2004b).

There is a need for a social sciences approach with Tourette Syndrome research. Firstly, the social sciences, more so than the medical approaches, has a much richer recent history of implementing the social model of disability within disability-based research (Hughes, 2009; Oliver, 2013; The Union of the Physically Impaired against Segregation & The Disability Alliance, 1975). However, when it comes to Tourette Syndrome research, even social scientists by discipline might find themselves publishing

in medical journals (Bervoets *et al.*, 2023; Conelea *et al.*, 2022; Jones, 2023)<sup>3</sup>. The problem with this, however, is that medical journals typically feature articles that feature a medical model of disability. For example, the language of aiming to “evaluate the social and personal cost of living with TS” (Malli *et al.*, 2019: 819) or Chang *et al.* (2007) who argue that there are misconceptions surrounding the *treatment* of tics and consider disability a personal or individual thing to be treated rather than considering the role of society, as per the social model. These medicalised approaches to Tourette Syndrome miss the importance of considering wider society and the processes that work to disable people. A social science approach that considers the social model of disability (at a minimum) from the outset is key for ensuring that support services in particular are designed in ways that are empowering, productive, and focused on the needs and desires of the tourettic community ourselves. This thesis, in part, addresses this and takes a social science and beyond-social model of disability-based approach to addressing some key themes that arise from data about the lived experiences of adults who have been diagnosed with Tourette Syndrome.

Contextually then, this thesis comes out of a gap in literature that considers the adulthood experiences of Tourette Syndrome along with a significant need for more participatory, social-science, and more-than-social model of disability-inclined approaches to Tourette Syndrome research. My methodological approach for this project was significantly underpinned by a desire to be as participatory as possible. Looking back to Chapter 2 and the highlighting of the ways in which non-representational approaches to disability research have been vital in uncovering the need for this specific project, it is important to here also acknowledge the decisions made methodologically that will be discussed in this chapter could be argued to be particularly representational in their approach. Once more, here is it valuable to reaffirm the fact that existing literature on Tourette Syndrome is incredibly limited, and so whilst we might initially consider representational approaches to disability as outdated, we need representational approaches to the research of Tourette Syndrome in order to allow us to move forwards and *catch up* with other disability research. Approaches discussed in this chapter, particularly the use of interviews, is distinctly representational, but is a necessity in order

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<sup>3</sup> Not *all* authors featured in the papers are social scientists, but the large majority of these are. Of note is Diana Beljaars who also currently works in the Medical Sciences department of Swansea University. She has a background in Human Geography, and has particular interest in Tourette Syndrome.

to allow us to further the research of Tourette Syndrome With this in mind, the rest of the chapter seeks to outline the specific methodological processes of this PhD research project.

### 3.1.5. Ethical Approval Process

The project proposal underwent a strict ethical approval process within Newcastle University, and consisted of sharing consent forms (Appendix a), information sheets (Appendix b), risk assessments (Appendix c), and a broader outline of the project that this chapter as a whole builds on. The ethics application considered the ways in which the research would be conducted in ways that were participatory-inspired and in collaboration with the charity *TIC-Hull*. The project received approval by the Faculty of Humanities and Social Sciences Ethics Committee on 28<sup>th</sup> August 2021, with the recruitment and data collection beginning shortly afterwards. This ethics application took into account COVID-19 within its risk assessment, given the landscape of the pandemic in the UK at the time of research inception, data collection, analysis and writing.

### 3.1.6 COVID-19 Statement

Contextually, it is important here to acknowledge that whilst my desires were to be as participatory as possible, COVID-19 had a significant influence over the ways and extent to which I was able to follow through with participatory aspects of the project. The research began in October 2020 and continued through until the submission of this thesis in December 2024. Below, I provide a short summary of key dates noted in my research diary that had direct impact on the research.

*Table 1: A timeline of COVID-19's impact on the research project*

Date	COVID-19 Relevance	Research Relevance
5 <sup>th</sup> November 2020	2 <sup>nd</sup> national lockdown in UK	Planned visits to TIC Hull monthly meetings cancelled, limited access to university resources
19 <sup>th</sup> December 2020	South East England and London placed on a Tier 4 'Stay at Home' lockdown	I was briefly living in an area effected by Tier 4 lockdowns at the time

29 <sup>th</sup> March 2021	Outdoor gatherings of 6 people / 2 households allowed	TIC Hull staff returning to socially distanced work, but meetings still based online
10 <sup>th</sup> December 2021	Facemasks become compulsory in many venues	Many stop attending in person meetings at TIC-Hull due to their decision to not require facemasks. Advisory focus groups take place online. Zoom-based interviews begin.
11 <sup>th</sup> January 2022	No longer need PCR tests to confirm positive lateral flow tests	Many participants and others stop taking lateral flow tests in order to avoid needing to isolate
24 <sup>th</sup> January 2022	Vaccinated people no longer required to take lateral flow tests before entering events, venues, etc	In person activities become easier, venues begin getting busier, and TIC Hull monthly meetings become busy. Zine workshop is able to be arranged but is postponed a few times due to COVID infections amongst participants.
24 <sup>th</sup> February 2022	All domestic legal COVID restrictions officially lifted in England	COVID-19 infections still a risk, participants and myself still not fully comfortable with in person activities. I continued to encourage the use of masks where possible in research spaces.

Further to the timeline shown in Table 1, even to this day, there has been a significant decline in the number of folks who attend in-person support groups with TIC-Hull in comparison to pre-pandemic numbers. Whilst COVID-19 affected all aspects of the project, it was particularly influential in the way that data collection was carried out. Advisory focus groups were held online. I had originally hoped to hold the advisory focus group with TIC Hull members in person, but this was not possible with restrictions, COVID-19 infection risk, and so on. Further to this, there were multiple instances whereby I took time off due to COVID-19 infections myself. This also had an impact on delaying certain interviews, particularly when it came to following up after the zine-making workshop. It is important to realise that whilst the majority of data collection did not occur during the 'height' of COVID-19 lockdowns, the fallout from them had a significant impact, whether in causing possible participants to be more wary of being involved in things such as workshops, or more generally having less time and energy to spend taking part in the project at the same time as adjusting back into post-lockdown life. These impacts were felt in all aspects of the project, and still continue to be felt.

As touched on during Chapter 2, during COVID-19's peak there was a particular narrative that surfaced surrounding the 'sudden onset' of 'tic like behaviours' in teenage girls, with many discussions surrounding COVID-19 and Tourette Syndrome being published academically. Further to this, there has been further fallout in the reinforcing of these narratives by the broader media, in newspapers, documentaries, and in online spaces. As a result of this, COVID-19 not only had practical implications on the project, such as in the additional safeguarding and risk assessing measures, or delays to the project, but also played a role in influencing the project thematically. Because of this, key themes that arose included stigma and specifically the representation of Tourette Syndrome in media and digital spaces.

### **3.2 Sampling**

This section shall attend to sampling practices including participant demographics, qualifying criteria, and recruitment methods used in order to provide context for this project.

### 3.2.1 Demographics

This project involved 36 adults who all have a diagnosis of Tourette Syndrome. The demographic makeup of the participants involved on the project is relatively diverse as far as gender goes. Participant gender identity was as follows:

- 44.4% Cisgender Female (n=16)
- 38.8% Cisgender Male (n=14)
- 5.5% Non-binary (n=2)
- 5.5% Transgender Male (n=2)
- 2.7% Transgender Female (n=1)

Whilst not all participants were based in the UK, the large majority were. When compared to UK census data, the gender diversity in this project is significant. However, in terms of age and ethnicity, the participants from this project were not as diverse. The large majority of participants were young adults between the ages of 18 and 30 (57.4%, n=20). It is important to acknowledge that age and ethnicity are likely to be less diversely represented in this research in part due to diagnostic biases. Tourette Syndrome diagnoses are most often given during childhood, and global majority ethnic people are less likely to be diagnosed with Tourette Syndrome than their white counterparts<sup>4</sup> (Dy-Hollins *et al.*, 2024; Kano *et al.*, 1998; Rodin *et al.*, 2021; Yang *et al.*, 2016). With this in mind, the participants demographics meant that the data collected was particularly white (86.1%, n=31<sup>5</sup>).

All participant experiences have been taken into account during the analysis of the data collected for this project. However, there were 6 participants who make a repeated appearance in the analysis and discussions in this thesis due to their extensive accounts of their experiences. These participants also provided a significant amount of data, given that many engaged with every single stage of the project, and all forms of data collection. For the purpose of context, it feels appropriate to introduce these specific participants in detail here:

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<sup>4</sup> It is important to reiterate here that whilst global majority ethnic people are less likely to receive a diagnosis with Tourette Syndrome, this does *not* imply that they are less likely to have Tourette Syndrome

<sup>5</sup> These statistics for white participants include the categories of white British, white Australian, white European and white American.

**Bella**

Bella is a queer, trans-woman in her 30s from the North of England, who was particularly involved in Tourette Syndrome awareness raising and volunteer work at the time of data collection. As will be explored later in this thesis, in the early phases of the project Bella did not use any mobility aids. However, she went through the process of becoming a full-time wheelchair user as the project progressed, and so shared particularly insightful accounts of the differences between her experiences prior to, and following, being a full-time wheelchair user with Tourette Syndrome in public spaces. Bella is a very confident woman and was particularly excited about the project.

**Stacey**

Stacey is a queer, non-binary musical theatre student from the North of England in their early-20s and is particularly engaged in social media content creation, where they raise awareness about Tourette Syndrome and their other comorbid diagnoses. They are an ambulatory mobility aid user (powered wheelchairs, walking sticks, crutches) and they have a lot of valuable insights regarding stigma and Tourette Syndrome.

**Pete**

Pete is a heterosexual male high school teacher from the North of England, who is in his 30s. He is married to somebody who does not have Tourette Syndrome, and he thoroughly enjoys all things creative, such as DIY and creative writing (which became particularly apparent during the zine-making workshops). Pete is confident and open about his tics, and had some particularly interesting insights about organisation, routine, and public spaces.

**Yebby**

Yebby is a queer woman in her early 20s from the North of England, who was forced to quit her job in childcare when she developed coprolalia. She volunteers for a Tourette Syndrome awareness charity, and thoroughly enjoys drawing and generally any creative activities. Yebby is an ambulatory mobility aid user, and throughout the course of the research she became significantly more confident in her identity as disabled, which showed through repeated interviews and her engagement in the zine workshop.

### **Bri**

Bri is a queer woman from the North of England who is currently a university student. She is in her early 20s and is in a romantic relationship with her full-time carer. Bri has been very engaged in social media spaces relating to Tourette Syndrome and has previously worked on various campaigns to raise awareness for Tourette Syndrome. Bri is shy and worries about interactions with other people that might happen within public spaces. She is very creative, and particularly enjoys poetry.

### **Porkchop**

Porkchop is a quiet, single, heterosexual man in his early 20s from the North of England who is unemployed. He is a big fan of videogames and art, and spends most of his time with his dogs in his art studio at home. Porkchop's tics are, for the most part, subtle and not always identifiable to people. This means that many of the experiences he shared with me offered particular insights into Tourettic experiences of invisible disability. He occasionally volunteers at his local Tourette Syndrome support group, using his art skills to help decorate the venue.

Some of these six participants were already good friends with each other, and so many experiences shared with me involved each other. This group in particular were engaged in a significant amount of the research project and played a fundamental part in determining the key foci of this thesis and its arguments. Their names will appear consistently throughout the following chapters.

The pseudonyms listed above, along with all other pseudonyms that will be mentioned in this project, were chosen by the participants themselves. I made a distinct choice to not assign pseudonyms myself, as I wanted to ensure that participants were able to represent themselves in as many aspects of the research as possible. Self-representation, rather than representation by an organisation or individual, is an important part of participatory action research (Pain, 2004) and so the act of participants choosing their own pseudonyms was one of the ways in which I was inspired by participatory approaches to this research. For example, one participant 'Tabitha Crumbshaw' chose this pseudonym because she feels like it is her ticcy alter-ego, who is

a *Tory*<sup>6</sup> and she stated that this alter ego says what she very much does *not* agree with. Similarly, Porckhop felt that his chosen pseudonym represented his larger-than-life personality and his hatred of vegetables. By engaging in the practice of participants self-allocating their own pseudonyms, it allows a sense of ownership to be retained when their stories are shared in these anonymised research spaces – this is a distinctly participatory-inspired approach.

### 3.2.2 Qualifying criteria

For this project, it was decided that because of a lack of existing literature on adulthood experiences of Tourette Syndrome, only people of a minimum age of 18 would be considered to take part in the research. This approach not only allowed me to focus on adulthood experiences, but also to go through ethical approval processes more quickly given that I was not including minors in the research. Given the time-restrictions of the PhD programme, being able to start the recruitment process as early as possible was particularly beneficial for research into Tourette Syndrome, given that the tourettic community is very isolated and not very well connected on the whole. Further to this, I want to acknowledge that receiving a diagnosis of Tourette Syndrome is not an easy, nor speedy process. This is particularly the case during adulthood. As a result, I did not feel that it would be appropriate or ethical of me to ask for any proof of diagnosis during the recruitment process. Having worked with TS charities and service providers for many years, I have come to know that many people with Tourette Syndrome are unable to access diagnosis for many years and this is particularly the case when trying to receive a diagnosis after the age of 18. Regarding the qualifying criteria for the project then, this means that when recruiting I asked people if they had Tourette Syndrome<sup>7</sup>, but did not ask for any form of proof.

What is particularly interesting to note here is that as the project progressed and more awareness of the research was built across Tourette Syndrome communities (and their non-tourettic stakeholders) there were a significant number of people who were

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<sup>6</sup> Tory here implies Conservative and right wing-leaning, politically. The language of ‘Tory’ mirrors that used by Tabitha.

<sup>7</sup> Regarding disability I generally use identity first language (ie ‘disabled person’, not ‘person with a disability’). However, there is no standard or widely used language to refer to people with a diagnosis of Tourette Syndrome. For example, with autism you might have ‘autistic person’. I personally use the language of ‘tourettic person’, but I am aware that this is not widely used, and so during recruitment in particular it made the most sense to use the language of *having* Tourette Syndrome.

turned away when asking to participate. These can be split into two main categories: (1) children whose parents were very keen for me to include their under 18 children within the research, and (2) non-Tourette stakeholders in Tourette Syndrome (parents, carers, siblings, etc) who wanted to share their own experiences of Tourette Syndrome as non-Tourette people themselves. The need for me to turn down requests of participation to under-18s with Tourette Syndrome and non-Tourette stakeholders in Tourette Syndrome was a frequent occurrence that speaks largely to the current focus of Tourette Syndrome research. Despite calls being made that were very clear in qualifying criteria for the project (adults over the age of 18 who have a diagnosis of Tourette Syndrome), there were 26 individuals instances whereby I had to reject people from the study for not fitting the criteria. Every request made by a non-Tourette person was rejected, whether in trying to get their child into the research or in trying to be involved themselves. The fact that these situations arose so frequently highlights the assumptions being made by people about what the focus of Tourette Syndrome research usually is – child-focused and prioritising non-Tourette adult voices when considering experience-based research.

Further to this, there were some restrictions on the numbers of participants due to concerns over the research not being based within a medical sciences department. Whilst the project surpassed expectations in terms of the number of participants I had hoped to recruit – 36 participants with a goal of 30 participants at a minimum – it is important to acknowledge this concern. The key concern in this regard came exclusively from touretic people of 40 years and older. Specific demographic information was not collected here, given that these people did not sign or fill out a consent form. Notably, questions asked included ‘Why did the medical sciences department reject the ethics approval?’, and ‘Why aren’t you affiliated with an NHS project?’. This is representative of the public understanding of Tourette Syndrome, and expectations of what many feel that the goals and aims of Tourette Syndrome research *should* be. I expect that this contributed to the slight overrepresentation of young adults within the research, and also raises questions about age-based differences that I was not able to comment on within this project’s scope as a result of this skew. As explored in Chapter 2’s literature review, funding is largely reserved for projects that aim to cure and/or *treat* Tourette Syndrome in line with the medical model of disability. There were multiple people who reached out to me expressing concern over the project, upon finding out that it was based within the

School of Geography, Politics and Sociology. Many also expressed expectations of ‘future’ stages of the research to involve a search for a cure for Tourette Syndrome, following this research’s assumed pilot study phase. What was particularly interesting to note is that the large majority of these questions were from non-Touretic stakeholders in Tourette Syndrome. It was non-Touretic people who expressed specific concerns over these questions and confusions, whereas Touretic people had expectations of some kind of ‘treatment’ phase for the project whilst not being concerned when finding out that this was not the case. There were even some instances where I was asked at what point the provisional participants in question were going to be able to try ‘the TS bracelet device’. By this, what was being referred to was ‘Neupulse’.

Neupulse is a wearable wristband that allows the user to self-administer electric shocks to stimulate the median nerve. The aim is that when the user experiences premonitory urge in a situation where they wish to suppress, they self-administer the shock. This device has been significantly advertised and promoted by Tourettes Action in particular, with webinars, updates, and even ‘accreditations’ to say that the company creating the device was ‘TS friendly’ (McClounan, 2023a, 2023b; Tourettes Action, 2023) and had dominated headlines and social media spaces throughout the duration of this research being carried out. As a result, a lot of public perception is that [his](#) research is *the* piece to watch or that if Tourette Syndrome research is happening it is exclusively this project, as evidenced with some of the common misunderstandings during the recruitment stage of this project. The implications of this were significant enough for this misconception about the research project to cause confusion despite the clear, concise explanation of the research topic on the promotional materials and in the information sheets that were provided to all who expressed an interest in participating. It would appear that the medical-model-aligned focus on cure and treatment, combined with the significant advertisement of the NeuPulse project, and misconceptions surrounding the value of social sciences within disability research contributed to the difficulties faced throughout the recruitment phase.

### **3.2.3 Recruitment**

The project had a total number of 36 participants, who were all involved in varying elements of the project. *Table 2* highlights this, and shows that out of the 36 participants,

31 took part in an interview, 7 took part in follow up interviews, 10 took part in advisory focus groups, and 6 took part in the zine-making workshop.

*Table 2: Breakdown of number of participants involved in each stage of the project*

Pseudonym	Focus Group	Interview	Workshop
Porkchop	1	2	Y
Leesh	0	1	N
Stacey	1	2	Y
Stevo	1	2	N
Kacy	1	1	N
Madge	1	1	N
Pete	1	2	Y
Adrian	0	1	N
Bri	0	2	Y
Bella	0	2	Y
Tabitha Crumbshaw	0	1	N
Leonard	0	1	N
Joey	0	1	N
Ricki	0	1	N
Milly-Anne	0	1	N
Mark	0	1	N
Simon	0	1	N
Yebby	0	2	Y
Gee	0	1	N
Eleanor	1	0	N
Ace	1	0	N
Dillon	1	0	N
Tia	1	0	N
Charles	0	1	N
Mels	0	1	N
Edward	0	1	N
Sugar Tits	0	1	N
Draven	0	1	N
Lorna	0	1	N
[ktatis 3] 3قطايطيس	0	1	N
Lizzie	0	1	N
Mary	0	1	N
Nesta Nirmala	0	1	N
River	0	1	N
Darren	0	1	N

Methods of recruitment adopted for this project were primarily via online spaces, with word of mouth playing a key part within the scope of TIC Hull and its members. Flyers and call-outs were distributed through TIC-Hull's mailing lists, and within their public social media platforms, including Facebook and Instagram by Kim Mitchell (CEO); emails were signed off by Kim, as CEO, whereas public posts were made under the TIC-Hull charity branding without any specific name to accredit to the posts – though the distributed flyers did specify that I was the researcher to contact for more information. Flyers and call-outs were also distributed in TIC-Hull's private Facebook community groups, by me as a fellow member of the charity, and this is where the majority of TIC-Hull based respondents were recruited from. Further to this, I developed rapport with members of TIC-Hull through regularly attending their adult support groups as a service user myself, as well as through volunteering with the charity. This rapport helped me to build relationships and resulted in conversations about my research naturally arising and therefore also opportunities to recruit via word of mouth amongst TIC-Hull members. Aside from using the platforms available to me through my collaboration with TIC-Hull, I also reached out to national TS awareness charity 'Tourettes Action', who shared my flyer on their social media platforms much later on in the recruitment phase of the project, particularly those of my call for trans and global majority ethnic<sup>8</sup> participants. Participants were given an information sheet (Appendix b) and consent form (Appendix a) to sign before taking part in the research.

Working with existing networks and charities relating to Tourette Syndrome was extremely important in the context of the isolation and stigma associated with Tourette Syndrome. This isolation and stigma had key implications of the challenging process of recruiting participants and the importance of working with institutional partners where possible. Chapter 6 in particular will unpack some of the processes surrounding loneliness and isolation, but in short there is no lack of literature stating that the Tourettic community is not very well connected, and that a core element of Tourettic experience is isolation. With this in mind, practically it is very important to work with existing networks – however limited they are – to ensure the reach of as many members of the Tourettic

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<sup>8</sup> The promotional material used the language of Black and Minority Ethnic (BAME) as it is a much more widely understood term. I acknowledge the limitations and restrictions that are tied up with BAME as a term, but I felt that using 'Global Majority Ethnic' would not have been as effective during the recruitment phase.

community as possible. However, I also wanted to ensure that I was not exclusively recruiting people who were *plugged into* communities of service providers and charitable services, as I know that the experiences of those who are not linked with any existing communities would likely be very different and offer a more well-rounded perspective. Further to this, I knew from previous research findings when completing my MA programme that there was some existing distrust that surrounded national scale organisations by some members of the Tourettic community and so I wanted to ensure that whilst I was engaging with the charity, I was also being clear about my independence from them. TIC-Hull, as a newer organisation, were significantly less well-known, which meant that there were not likely to be as many concerns about their practices, or the same levels of distrust as was the case with Tourettes Action.

This proved to be a productive partnership, as there were some instances during the recruitment phase where people contacted me with replies such as “As long as you’re not involved with Tourettes Action I’m happy to participate”. Whilst there was some advertisement used through Tourettes Action, they were not involved in the project, research design, or analysis and have no access to the data – this was made clear to participants prior to signing consent forms. Drawing upon my existing networks also proved beneficial, and allowed a much broader representation of Tourette Syndrome, regarding geographical location within the UK. Knowing that having a pre-existing relationship was incredibly effective in the recruitment process, I was sure to start building rapport with TIC-Hull and its members prior to actively recruiting participants for the project. Building genuine relationships through attending support groups, keeping in regular contact with old Tourettic acquaintances, and through actively working to facilitate community building in a variety of ways was an incredibly important facilitating factor for recruitment. Combining this with digital and in-person rapport-building was incredibly important to ensure as large a reach as possible within a notoriously isolated community (cf. Malli *et al.*, 2019). Keeping in contact with community members in these ways allowed for discussions about the research occurring much more naturally, which added to perceptions of the project as authentic and not-so-exploitative in its practice – something which proved important to participants when discussing this in and in-between interviews.

Ultimately, the most fruitful method of recruitment for the project was through the use of my own online networks that were external to TIC-Hull. Through previous research connections made during research conducted for an MA degree in Cultural Geography (Research) at Royal Holloway University of London, a successful private Facebook group for UK-based adults with a diagnosis of Tourette Syndrome was created. At the time of writing, this group consists of 225 members who have confirmed that they have a diagnosis of Tourette Syndrome and are either based in the UK or have reason to travel to the UK on a regular basis. The group's level of activity waxes and wanes, but posts asking for advice, arranging meet-ups, and sharing their experiences are the ways in which the group is most commonly used. The group has previously been used to recruit participants for my research, and to provide updates on the progress of research, published works, etc. Further to this, through my previous work in TS advocacy online I began the project with a decent number of X<sup>9</sup>, Twitch<sup>10</sup> and TikTok followers and Facebook connections who were also adults with a diagnosis of Tourette Syndrome. Through sharing the promotional material for the research via these routes based on previously conducted research, I had significant uptake of particularly those based in London and the Southeast of London due to the fact that my previous research was conducted in those areas. However, the use of particularly X and Twitch were key in helping to improve the reach of recruitment advertisements.

In particular, using a range of social media platforms to recruit participants was a key part of attempting to increase the age range of the project participants. Notably, in 2023 around 35% of TikTok users were aged between 18-34<sup>11</sup>(Statistica, 2024). Comparatively, in 2023 around 53% of Facebook users were over the age of 35, inclusive of under-18 platform users (Herd Digital, 2024). Using TikTok in particular allowed for better reach of young adults in the recruitment phase, whilst Facebook in particular proved more useful for reaching those who would not be considered as 'young adults'. This was reflected in participants who did participate in the project. Whilst there was definitely a larger number of young adult participants than otherwise, this is likely due to other extraneous factors such as commonality of Tourette Syndrome diagnosis, etc as

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<sup>9</sup> Previously known as 'Twitter'

<sup>10</sup> A live-streaming platform used commonly for video gaming, but also for co-working, podcasting and educational purposes

<sup>11</sup> It is important to consider here that around 50% of TikTok users are under the age of 18 in this data set, meaning that 35% is a significant majority of those who might fit the 18+ criteria of this research project.

previously discussed. I believe that using a range of recruitment methods is what allowed for the wider reach and worked to lessen the young adult skew within this dataset.

### **3.3 Data collection**

The methods used to collect data in this project were chosen for specific reasons – the approaches taken were based upon extensive literature reviewing and planning to ensure the safeguarding of participants, an ethical research approach, and to ensure a high quality and amount of data was collected prior to the analytical phase of the project. This section in particular outlines the specific data collection methods that were used (focus groups, interviews and a zineing workshop) before following up with specific justification and ethical considerations of these chosen methodologies.

#### **3.3.1 Outlining data collection methods**

##### **Advisory Focus Groups**

The research took a mixed-methods approach, implementing a combination of focus groups, interviews (including follow ups), and zine making. The first stage of the project, however, used 2 semi-structured focus groups (Appendix d) that acted in an advisory manner to help shape the focus of the project to ensure that participants themselves were participating in the sense that topics and themes that were most important to them were the ones being given space within the research. Using focus groups in advisory capacities has proven a useful approach in line with collaborative and participatory research frequently (cf. Brady *et al.*, 2023; Isham *et al.*, 2019; Bagnoli & Clark, 2010), hence the decision to implement them. The first advisory group consisted of 6 adults with a diagnosis of Tourette Syndrome, ranging in age from 19-65 years old, with the UK, Netherlands, Australia and the USA being represented. These experts-by-experience were all at differing stages of their *lifecourse* of TS, with some having been recently diagnosed, and others having had a diagnosis many years ago. The second advisory group consisted entirely of members of TIC Hull. This advisory focus group consisted of 4 people<sup>12</sup>, of ages ranging from 22-33 years old, and all of whom were based in the East Yorkshire and Humberside area. All of this group's participants had received a diagnosis within the last 5 years, and so this will have had an effect on issues and themes

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<sup>12</sup> 3 more people had initially signed up to attend this focus group, but 1 did not show up and did not participate in the rest of the project, whereas 2 others were unable to attend due to unforeseen circumstances and so an interview was conducted with them in place.

that were most important for the project to consider within this group. These focus groups were recorded on Zoom, and audio transcribed manually by myself on Microsoft Word, prior to data analysis.

Initially, focus groups were used in a more advisory way to try and gather opinion and preference for the focus of this project moving forwards, hence my referring to them as *advisory focus groups*, to ensure that within the scope of the PhD programme the project was as participatory as possible by having participant engagement in project foci from the outset. The participants of the advisory focus groups, for the most part, were also participants in other aspects of the project too. This approach has proven successful in previously published research and is a common approach in attempts to shape public policy and in the production of new guidelines surrounding health and disability. This can be with those who might be classed as patients, or with stakeholders more generally speaking, but have proven useful in many instances in ensuring the wishes of the research population are kept in mind throughout the project (Caldwell *et al.*, 2009; Chan *et al.*, 2021; Lehoux *et al.*, 2006; van Eyk *et al.*, 2020). Furthermore, the use of focus groups as *advisory* aspects to the research was very much in line with my overall project aims of being as inclusive, participatory and as collaborative as possible.

The advisory focus groups were a fundamental part in shaping the research as it progressed. In particular, these focus groups demonstrated the ways in which there was an inherent underlying uncomfortability with physical public spaces, which led to people being much more engaged in the use of social media and digital spaces otherwise. This might be due to general inaccessibility of the built environment for those who relied on mobility aids, or the ways in which a lot of work and effort had to be used in order to not feel *seen* or to not *stick out* in public spaces. The experiences and anecdotes shared in these advisory focus groups were particularly varied, but they all aligned with a general uncomfortability in and around public spaces, the ways in which adults are forgotten in most Tourette Syndrome discourse, and how the digital is an important part of their everyday experiences of public space. These advisory groups led to further inquiry into these topics in particular as semi-structured interviews and zine workshop plans were designed, and ultimately led to the specific analysis and conclusions made throughout this thesis

### **Semi-structured interviews**

The second element of data collection key to the project was semi-structured interviews (Appendix e) with individual tourettic adults. These interviews were primarily conducted through Zoom (n=36), in an attempt to be as cautious as possible regarding COVID-19 and possible spreading of the virus. Like the advisory focus groups, the Zoom interviews were recorded on Zoom and then transcribed via Microsoft Word. For interviews that occurred in-person (n=2) they took place at TIC-Hull's *Hub* in Hull, UK. We used a private, sound-proofed room and the interviews were recorded on a work mobile phone to keep the recordings separate from my own personal files on my main mobile phone. These, again, were then transcribed manually on Microsoft Word. Out of the 38 interviews in total, 7 were follow up interviews. These follow up interviews were a combination of follow-ups from focus group discussions and zine-making workshops, and were also semi-structured in design, though all had different *plans* that were bespoke to each specific participant. Other participants were reached out to for further follow up interviews, but did not have the capacity to be able to commit to another interview due to other commitments.

Following on from focus groups, using interviews in combination with focus groups has been a very standard practice within the social sciences, and particularly with regards to health and disability-related themes (Cambridge & McCarthy, 2001; Khan *et al.*, 1991). In particular, I wanted to ensure that participants had the opportunity to share their experiences in much greater depth than a focus group might allow, both in terms of feeling comfortable to share more intersectional experiences of Tourette Syndrome, but also in the interests of time and care relating to sensitive topics of inquiry (cf. Goenthals *et al.*, 2015; Kavanaugh & Ayres, 1998; Brayda & Boyce, 2014). In order to allow participants the freedom and flexibility of discussing what was most important to them, I was sure to keep to the semi-structured style of interviewing. Experience-based research requires a depth of data that I argue only interviews (and follow-up interviews) can offer when used in combination with other methods such as focus groups, zine-making, etc., and that has been used in previous research also (Cuenca *et al.*, 2015; Hansen & Philo, 2007; Mudge *et al.*, 2013; Persson & Rydén, 2006). Additionally, given that the interview space was more private it allowed for people to ask questions, and particularly share their thoughts and opinions that perhaps did not match up with those of people in the focus groups. Going

into the research I was aware that understandings and experiences of Tourette Syndrome would be very varied and, in some instances, contrasting or contradictory to each other. As a result, it was extremely important to include individual interviews. Doing so allowed me to acknowledge the *mess*, to sit with it, and implement it within my forthcoming analysis of the data.

### **Zineing workshop**

The third data collection method used in this research was the facilitation of a ~3 hour zine workshop. Whilst this section aims to give a brief overview of the practicalities of the approach of zineing that took place, as well as highlight the ways in which this was key in terms of the participatory aims of the project, fuller discussion of zines and zineing will take place in Chapter 7 of this thesis. This is due to the fact that analysis of the method itself is the focus of that chapter, and therefore makes most sense to save this fuller discussion for later.

Provisionally planned by Zeke Woodley<sup>13</sup> and myself, with those who would be attending the workshops being consulted. Not everybody gave feedback about how they wanted the workshops to look, but we were unable to financially reimburse participants for anything more than travel costs and so I made the choice not to push too hard for participants to engage within this additional unpaid labour. The workshop was hosted at TIC Hull, as all attendees were members of the charity, and so this kept workshop costs to a minimum. All participants created their own zines, and creatively responded to workshop prompts (Appendix f) before working together to create a collaboratively co-produced zine, titled *Tic Tic Boom!*

In creating the final zine, curation could be said to be used as a method within the zineing workshop. Working with Zeke Woodley and the workshop participants, we decided that we would ensure that all of the content was included in the zine, even down to small doodles that were left behind on the day. The curation of the collaborative zine *Tic Tic Boom!* was an iterative process. We initially asked all participants if they were comfortable including everything in the zine, and everybody was very keen to include all of their work where possible. In this instance, curation did not look like making decisions about what to cut from the final zine, but rather the ordering and placement and

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<sup>13</sup> Zineing workshop facilitator pseudonym

repurposing of individual artworks for the collaborative zine. Participants were offered the opportunity to be as involved or as non-involved in the curation process as they wished to be and were vital in the curation process in emphasising the key points and elements of their experiences that they wanted to portray, the positioning and ordering of content, and so on. The curation process was an iterative and collaborative process that thankfully went very smoothly thanks in part to Zeke Woodley and his extensive experience working on projects like these.

Once more, zineing and the use of a zineing workshop will be discussed in much greater depth in Chapter 6, but for the purpose of this chapter, zines are incredibly powerful tools that allow for community building and solidarity sharing – both of which were wider aims for the project – whilst also offering an accessible, non-verbal way to communicate complex ideas in creative ways. It also spoke volumes to the collaborative aims of the project and provided a huge variety of interesting data to work with when it comes to analysis. Others have used zine-based methods when working in participatory and collaborative ways (French & Curd, 2022; Velasco *et al.*, 2020a), and this project was inspired by the plethora of particularly *creative geographies* literature that pre-exists this research.

Combining these methods proved to be a successful way of gathering a diverse data set that had depth and nuance, and that was applicable to all research questions and wider aims of the project.

### **3.4 Data analysis**

Similarly to the data collection methods used, analytical approaches were specifically chosen ~~bearing~~ in mind previous research approaches found in published literature, and also my own understanding and preferences of analysis techniques. Some of these techniques that will be discussed in this section were chosen as I have had proven success with them in the past and were those that I had found particularly enjoyable. This is something of particular importance for me as a neurodivergent researcher. Traditional analytical methods might not be the best fit for every researcher, and the approaches that will be outlined and justified in this section are partly influenced by this too. As somebody with lived experience of Tourette Syndrome myself, as this chapter will go on to outline, I felt that it was important for me to make the analysis experience as enjoyable as possible given the likelihood of upsetting and/or triggering

experiences being shared with me. Doing so is an act of crippling the analysis and is an approach that I believe is in line with the participatory and crip-queer conceptual frameworking of this project. This section begins with an outline of analysis techniques used throughout the analysis phase of the project, as an iterative process, and follows up with justifications and ethical considerations of the decisions that were made.

#### **3.4.1 Annotation and transcription as analysis techniques**

During data collection, such as during focus groups and interviews, I conducted sessions with the help of session prompt sheets (Appendix d, e). Whilst conducting the interviews and focus groups, I made quick, shorthand notes on these prompt sheets as reminders of interesting points to come back to later in the sessions. These were done by hand, using either a pen and a piece of paper or an Apple Pencil on an iPad notes-writing app called GoodNotes 5 (writing on top of the prompt sheet document). During the zineing workshop, I made notes on my mobile phone's notes application. These notes consisted of key terms, phrases, stand out quotations, and so on. As the data collection phase progressed, these notes began to also include key words and themes that might link them to other interviews and focus groups that had already been conducted.

Following on from focus groups and interviews, I had these annotated prompt sheet next to me whilst manually transcribing recordings in Microsoft Word. I chose to manually transcribe all of the recordings, as I wanted to immerse myself in the data and get to know it very well. This was incredibly important, as I was dealing with a lot of in-depth data about individual experiences of Tourette Syndrome. By dealing with the transcription manually rather than automating it or outsourcing it, I was able to ensure that I was closely connected to each ~~participants'~~ ~~participant's~~ stories and experiences. By doing so I was able to distinctly remember participant accounts and not confuse people's complex stories and layered experiences. Whilst transcribing, I was continuously referring to the annotations made within the interview/focus group in question, and adding notes as to what might be interesting to ask more about or anything that perhaps needed some clarification during a follow up interview. By having this strategy for transcribing I was able to ensure I had a full understanding of all participants' comments and accounts made by participants, and that data was of enough depth to continue with analysis.

#### **3.4.2 Coding of Transcripts and Visual Data**

Following this, I used NVivo to do some initial coding. I read through transcripts and noted down themes and topics that were brought up multiple times. At the point of beginning the coding, I was still also collecting data. The coding process was very much iterative, and I intentionally used NVivo to highlight those initial key themes that began coming up to allow a broader overview of the data I had at any given moment. All transcripts went through multiple rounds of coding as the project continued and as new themes began to arise over the 6-month period of analysis; the coding was very much an iterative process. A full list of codes can be found in the appendices (Appendix g), but particularly important ones to mention here are as follows:

Table 3: Transcript coding matrix

Main Theme	Sub theme	Sub Theme	Sub Theme
Accessing public space	TS as beneficial	TS as limiting	-
Affect	-	-	-
Age	-	-	-
Anonymity	Positive	Negative	-
Publicity	Positive	Negative	-
Age	-	-	-
Community	Positive	Negative	-
Comorbidity	-	-	-
COVID-19	-	-	-
Disclosure	Symbolic disclosure	Verbal disclosure	-
Faking TS	-	-	-
Indicators of social difference	-	-	-
Disability aids	Mobility	Otherwise	-
Intersectionality	Ethnicity	Sexuality	Gender
Isolation	-	-	-
Media portrayal	Positive	Negative	-
Premonitory urge	Suppression of tics	Otherwise	-
Public transport	Positive	Negative	-
Raising awareness	-	-	-
Rhythm	-	-	-
Sensory	-	-	-
Services	Diagnosis	Support groups (digital)	Support groups (physical)
Social media	-	-	-
Stigma	-	-	-
Suggestibility	-	-	-

Once again, these codes were not exhaustive of all themes that were covered throughout the entire analysis phase but are representative of the initial coding process that occurred specifically in NVivo. These codes were used as starting points in later stages of analysis in mind-mapping too. As far as the use of NVivo and coding goes, I felt that the software was somewhat restrictive and was forcing me to categorise people's lived experiences in binary ways, when a lot of the time there were conflicting experiences that did not fit neatly into the codes in a way that I understood them. I felt this was somewhat restricting when trying to carry on with coding through NVivo, hence a switching to hand drawn mind maps, flow charts, and zines to analyse the data in a way that allowed me to feel significantly more connected to the data.

### **3.4.3 Analytical mind mapping**

To begin, I used the initial codes in NVivo as a starting point in order to give some initial structure to physical mind maps. It is important to note here that by *physical* I do also refer to mind-maps that were created on the GoodNotes 5 application for iPad, with the digital pencil. These mind maps consisted of not only extracts, quotations, observations and general notes from interviews and focus groups but also, at a later stage, extracts from the collaborative co-produced zine, *Tic Tic Boom!* These mind maps were continuously being reimagined as the project progressed, and this mode of analysis was very much an iterative and creative process (Appendix h).

Mind mapping has previously been used in published qualitative research, and there is academic literature that highlights the value of using mind-mapping methods. In a study by Kotob *et al.* (2016) they concluded the use of mind mapping as an analytical tool is a good tool for working with large amounts of qualitative data. Not only this, but they continue to write that "The power of the technique is not only in mapping individual interviews but also in creating integrative maps which can communicate the findings from numerous research participants." (p255). Mind mapping was particularly useful given ~~the~~ not only the sheer quantity of data, but also the variety (transcripts, poetry, drawings, collages as other visual data). Further to this, mind maps are very flexible and so do not have specific rules – they can be adapted in many ways. They have also been said to only have the rule of requiring imagination and thought (Buzan, 2006). The mind maps that I created helped me to acknowledge the intersecting and interconnected nature of even

the most contrasting experiences and allowed me to get to grips with the fuller picture of arguments that were relevant to the thesis research questions.

#### **3.4.4 Analytical zine-making**

As aforementioned, working with a significant amount of qualitative data of varying kinds is a complex process that requires acknowledging the extensive interconnectedness of said data. In order to ensure that in this I had a concise way of communicating, and therefore a strong understanding of the analysis that I was conducting, part of the analysis process for me was the creation of mini-zines to work through my ideas and findings. Creative approaches to summarising and *sitting-with* data such as journal writing and writing poetry with collected data is something that can foster creativity of the researcher, and zine-making is no different (Konecki, 2019); creatively engaging with the data throughout the analysis and not solely in the production of data or in its dissemination is something that was key for me to ensure that I was able to find new ways of understanding this complex, nuanced, and plentiful qualitative data.

These mini-zines (Appendix i) were also wonderful visual aids for when discussing current findings of the project with participants, charity research partners, and other academic colleagues who were interested in the project. They greatly assisted in inspiring conversation about my work, which was beneficial for working through the more complex arguments and points of analysis within the project. As aforementioned, one of the key goals of this project was to be as collaborative as possible with participants and with charity partner, *TIC Hull*. This meant keeping regular contact with these stakeholders throughout the research project, inclusive of during analysis stages. Having conversations with the people who this data was about regarding the findings at any point in the project was incredibly beneficial and generated not only excitement and enthusiasm for the project, but also resulted in a clearer understanding of the data on my part. Having these tactile *things* to consider was a powerful way of further immersing myself in the data, in ways that inspired these further conversations. Part of these conversations was using the zines that I had created as prompts to spark further discussion. Using the significant disseminatory potential of zines here throughout the analysis phase of the project proved incredibly valuable (Jones, 2024; Bagelman & Jones, 2023).

Further to familiarising myself with the data and developing greater understanding of said data through zine-facilitated conversations, zine making as a mode of analysis in the project was a key element of furthering the iterative approach to data analysis. None of these analytical methods took place in isolation, but particularly using zines to analyse the data allowed for creative engagement with the data that brought up new themes, codes, and avenues for further inquiry that perhaps would not have been realised should I have not engaged in the process. It also significantly helped in ensuring clarity and focus in analysis that is found within this thesis, and proved beneficial for thinking through complex ideas in concise ways that used minimal jargon for the benefit of funding applications being made by *TIC-Hull* in applying for further financial support to continue their adult-focused support-based services.

### **3.5 Changes and reflections**

With the methodological approaches in mind here, it's important to acknowledge that across the four-year course of this PhD research, hindsight has come through reflections on things that I wish I could have done differently, or things that perhaps did not pan out in the exact ways that I planned. This is somewhat an inevitability with projects that span multiple years, and so this section of the chapter will address some reflections regarding the project's limitations and the relevance of my positionality in *doing* this research. Further to this, it will round off with some comments surrounding the need for flexible and iterative approaches that were required to be taken when conducting this research. In doing so it offers context for the analysis to come, along with the scale of some of the claims to be made in forthcoming chapters.

#### **3.5.1 Limitations to the project**

Whilst overall I would argue that this research project has been a significant success, it is important to acknowledge the limitations to the project, inclusive of outcomes, claims being made, and so on. By acknowledging the limitations of the project, we are able to ensure that we have the full context needed to understand the extent to which claims are being made within the forthcoming analysis chapters of this thesis.

### **Representing the tourettic community**

Whilst there may have been a relatively diverse representation of gender and sexuality, there were two particular areas that were lacking in representation from the sample.

Firstly, it is important to acknowledge that the large majority of the participants were white British. Within the project, out of all participants who took part (n=36) only ~11% of those were not white (n=4). Given that I made specific efforts to recruit participants from outside of the United Kingdom and specific attempts to recruit global majority participants, I would argue that this skew here means that the experiences I talk about in this thesis are significantly based on white experiences. This means that there are limitations regarding the extent to which I am able to represent global majority experiences of Tourette Syndrome, and so I would argue that despite some analysis of these experiences to come, this is still a significant gap in literature and research more generally speaking.

Further to this, it is important to acknowledge that regarding demographics there is also a significant skew to younger generations within the project. 57% of participants were under the age of 30 and 43% were over the age of 30. This means that there is a significant skew in my data towards the experiences of young adults. In particular, only one participant was over the age of 60, and this was Madge who was 65 years old and living in the UK. Given that the UK state pension age is currently 66 years old for both men and women (Age UK, 2023), post-retirement experiences of Tourette Syndrome are significantly missing from the analysis and arguments made within this thesis. Unfortunately, this is representative of limited research that currently exists into adult experiences of Tourette Syndrome and is likely in part due to the changing levels and manifestations of stigma surrounding tics and tic disorders over time, meaning that there are likely to be many older adults who never received a diagnosis of Tourette Syndrome, despite having all of the symptoms required for diagnosis. Further to this, due to the significant absence of adulthood support services, as people continue to age they are likely to grow more and more distant from other Tourettic people. As aforementioned, a variety of recruitment techniques were used to attempt to reach a more diverse age range of participants such as the use of advertisement on social media platforms with significantly different target age groups, as well as using in-person recruitment strategies

and drawing upon pre-existing networks and rapport that I had previously built. However, despite this, there was still a significant skew towards young adult representation in the data, and so certain experiences that perhaps intersect with ageing with Tourette Syndrome are likely to be missing from the analysis.

### **Limited data collection**

Though a lot of data was gathered when combining all modes of data collection, it's important to acknowledge that follow up interviews and the zineing workshop were limited in their quantity. As aforementioned, I conducted a total of 7 follow up interviews. However, I did reach out to many participants inquiring about follow-up interviews. Nobody outright declined, but rather I did not receive any responses. As a result, this means that I often had a clearer understanding about certain participants' experiences, and therefore they appear much more present in the data analysis and arguments being made later in this thesis (particularly those who were individually introduced earlier in this chapter).

What is of particular significance in terms of considering limitations to the project here is the fact that only one zineing workshop was held. This was due to the expenses associated with the workshop, along with the fact that workshops were cancelled multiple times due to COVID-19 infections. Conducting one workshop meant that only 6 of the 36 participants were able to engage in this collaborative co-production of the zine, and so whilst claims being made based upon the workshop are still valid, the scale of these claims is restricted. Should I have been able to facilitate multiple workshops over a period of time, and perhaps even multiple workshops with the same participants, this would have opened up a much richer set of data for analysis. This may have fostered more of a possibility for focussing on the visual materials produced themselves. However, as Chapter 6 will go on to outline, this is not an entirely negative thing and this resulted in some findings that were specific to the workshop site itself as a space for fostering community and solidarity – two of the overall project aims. Reflecting on the singular workshop that was hosted, should the project have had multiple workshops it may have been possible to produce multiple collaborative zines that would perhaps have had very different foci. For example, the work produced in the workshop was very much focused around physical public spaces, with not much mention of the digital. It might have been

interesting to see more creative reflections on digital space to make even further comparisons.

Further to conducting more workshops, I would have liked to hold more follow up interviews with participants. I had reached out to many more participants for follow up interviews than I ended up conducting. If I was able to conduct more follow up interviews, particularly those with a larger gap in them due to the longer time period in which interviewing was conducted, it might have offered up interesting insights about the ways in which Touretic experiences of public space fluctuate significantly. This was suggested from the few follow up interviews that I did conduct, but having more data on this would have made for an interesting additional point of analysis that was backed up by much more data. Whilst some claims surrounding this will be made, the scale of these claims is restricted and I here argue that further research considering this would be incredibly generative of stronger, more evidenced claims.

#### **The extent of collaboration and participatory approaches**

As aforementioned, a key goal within this project was to be as participatory as possible with all stages of the project. A key element of participatory work is in the attempt to disrupt hierarchical relations as much as possible, and unfortunately the dynamics inherently present in the PhD programme are not facilitative of this. Firstly, participatory work, at its core, has a general aim of not taking an *in-and-out* approach to research. Participatory projects are generally expected to be long-term and to exist beyond the scope of the researcher's involvement.

Further to this, I think it is very important to acknowledge the power dynamics that come from the fact that through my involvement in this research I will be gaining a PhD qualification. The same ~~can not~~ cannot be said for participants of this research. They are not being financially reimbursed (other than for any travel costs), nor are they gaining qualifications. Whilst this is not something that is avoidable within the scope of my PhD programme and the funding requirements, it still is something I consider to be a significant limitation regarding broader project aims of being participatory and collaborative at any given opportunity.

One way that might have added to the extent to which I would argue this project is participatory would be to spend a greater amount of time in the advisory phase of the

project, conducting advisory focus groups. Due to time constraints, I was only able to conduct 2 initial advisory focus groups – the first of which had international representation, and the second of which consisted exclusively of TIC-Hull members. Whilst these were incredibly useful and had direct impact on the design of the remainder of the project, it would have been great to involve significantly more participants in this in order to increase the extent to which the project was participatory. For example, every single advisory focus group member was white. Having global majority ethnic participants involved in the advisory phase may have brought up different needs and hopes for the project as it continued. Further to this, the project could have been made more participatory by returning to the advisory group members in the later stages of the project, notably in the data analysis phases. Whilst it would have been ideal to have participants assist in the analysis, it's important to also acknowledge that part of participatory work involves not forcing or pressuring people to be more involved than they wish to be. With fewer time constraints, this might have been something I would have been able to explore in a lot more depth.

### **3.5.2 Positionality**

Regarding my positionality as researcher, it is important to clarify the context through which I came to be involved in this research, and how I developed these specific research interests. At the age of 13, I was diagnosed with Tourette Syndrome. However, in response to the psychologist's statement that I would *likely grow out of it by 18*, my parents tried to distract me from my tics (also at the psychologist's recommendations). Anytime I ticced, or had an increase in tics, I was encouraged to distract myself from them by reading a book. Unfortunately, this didn't have much of an effect, but my parents adamantly stood true to the psychologist's recommendations. They did the best that they could with the information that they were given – next to none. Through the advice to distract me from tics and to not talk about Tourette Syndrome, I was not made aware that I had ever received an official diagnosis. As a result, I was kept away from any Tourette Syndrome support that might have existed in my hometown out of fear that the tics would not disappear come my transition into adulthood. Not my own fear, but that of my parents, psychologists, and other medical professionals. School was tough, but I grew up and finished high school. I went to college after being bullied, hoping for a new start and for the first time the *silly noises* and *silly movements* I was doing didn't seem to be a problem.

I became known as *Tourette's Daniel*, as a way of identifying me from a crowd of others with the same name as me. Whilst this wasn't done maliciously, I felt a sense of guilt. I would tell people I had Tourette Syndrome because it was easier than explaining that I *probably* had Tourette Syndrome as I had all the symptoms but that I didn't have a diagnosis; the diagnosis was still unbeknown to me. However, I stayed away from any kind of Tourettic community, or anybody I knew who even had a twitch, out of fear that I'd be found out to be a fraud. I felt lonely and isolated. I didn't have to. At this point, I was involved in a local church and would attend regularly, volunteer playing music on stage, and was generally *plugged in* to the church community. The only kind of solace, as such, that I found was in people praying for me to be healed. Sometimes this was done out of genuine love and with good intentions. Sometimes I would have negative experiences that made the isolation even worse – imagine being told by a visiting preacher that you haven't been 'healed' from Tourette Syndrome yet because of a demon possessing you, or because you're holding on to unforgiveness of somebody and that you couldn't receive the *blessing* of healing until you cast out said devil, or worked hard to forgive these hypothetical, unknown people.

I finished college and was lucky enough to go to university to study BSc Human Geography – a course that felt like a 'real'-enough degree to make my parents happy. Throughout the course, I struggled. I didn't qualify for any disability support because of my assumed lack of any official diagnosis. I missed lectures because my tics worsened to a point where I was *too distracting*. They didn't record classes back then – it just wasn't something typically done. I spent most of my energy not focusing on final exams, but on suppressing my ever-worsening tics so they didn't distract others by echoing around the room with hundreds of students all silently working away. At some point in my final year, I somehow stumbled into applying to an MA in Cultural Geography as I was worried about heading into what I considered to be the 'real world' and was concerned over having to *deal with* tics outside of education. In this MA course, a lecturer taught me all about creative research methods and how bodies move in and around spaces. We learnt about how bodies were not accidentally moving through spaces, but that our movement was carefully choreographed, even subconsciously, and that every movement was intentional. I struggled with this and found myself unable to relate to what we were being taught. I thought about how none of my tics were intentional, and wondered what that would mean

for this teaching. It was then that I decided to conduct my MA dissertation research into Tourette Syndrome and the body. However, I wasn't sure that it was ethical for me to do such research as somebody who didn't have a diagnosis, as I wanted to use autoethnography. At this point, I really resonated with Tourette Syndrome but was still unaware of the official diagnosis that I'd had for 8 years at this point. I contacted my GP to ask for an official assessment, and to my surprise I received an email back that included a copy of my diagnosis from my teen years along with some very confused comments from the GP. I felt overwhelmed, thinking about how for all of these years I'd not been receiving any of the support that my official diagnosis of Tourette Syndrome was supposed to enable me to access; I thought about all the reasonable adjustments that might have been able to be made with my studies and various part time jobs; I thought about all the years that I felt needlessly guilty for telling people I had Tourette Syndrome. It completely re-contextualised everything I knew, and my understanding of space, place and my own body.

I conducted the research and found that the experiences that participants shared of support (or lack of support) surprised me. I began looking into adult experiences, specifically, and realised that there was a lot more to Tourette Syndrome and bodily movement that I didn't know. I had many years of *experiencing* Tourette Syndrome that I didn't understand. Participants would speak of their experiences in ways I couldn't relate to. I finished the dissertation and concluded that tics were not a thing to be considered as objectively bad. There was something about them that was affective, contributing to the way that the identity of place was constructed. However, I also concluded that this project was significantly larger than the scope of the MA dissertation allowed for. I worked for a few years, and all the while I was doing research into Tourette Syndrome from outside of the academy. I did a lot of work trying to make sense of my own experiences and realised that there was little to no published work on adulthood experiences. I did a lot of work over those years, trying to understand myself. I was chatting to a previous participant from my MA research who I stayed in touch with, and she suggested connecting me with TIC-Hull. We got chatting, and I ended up applying to a PhD at Newcastle University.

With the context of confused understandings of self, and what felt like many missed years of learning about Tourette Syndrome and of missed possibilities for support with education, we are brought to the onset of this research. With this in mind, it is key here to

outline and attempt to summarise the areas of my experience that have significant influence over my positionality:

(1) My lack of engagement with any educational or service-based support relating to Tourette Syndrome

To some extent, my lack of involvement in these educational or service-based support, and even my lack of involvement in any Tourettic community, growing up means that to some extent I have a strange separation from it. I do not have direct lived experience of growing up in services, or with any form of formal support, and this means that despite my lived experience of Tourette Syndrome, I still to some extent might be considered an outsider to these services, which will have an impact on the way that I view them.

(2) My expectations and subconscious expectations of loneliness in Tourettic experience

As per my aforementioned experiences of growing up, my understanding was that Tourette Syndrome is lonely. What characterised my experience was isolation, loneliness, and feeling like an outsider. I didn't know anybody with Tourette Syndrome, and though I wasn't aware of my diagnosis, I *was* aware that I had the relevant symptoms. In the midst of not being allowed to discuss tics, or even acknowledge them, and the bullying and harassment that I dealt with as a teenager I felt lonely. Realising that I had a diagnosis of Tourette Syndrome contextualised *why* I had felt so lonely. It felt as if Tourette Syndrome was the cause of that loneliness. Going into this project, I was very aware that my experiences of loneliness would likely have a subconscious influence over me noticing the theme of loneliness. Whilst this came up as a key theme, which will be discussed in more detail in Chapter 5, when it initially arose as a sub theme I was wary and concerned about my own bias. However, through adhering to my analysis strategy this came out still as a very strong theme. These accounts of loneliness were emotionally charged, and I knew they would bear emotional weight for me should they come up. Whilst I was cautious about potential bias towards noticing a theme of loneliness, I also leant into the expectation to hear some accounts of loneliness, and this allowed me to emotionally prepare for interviews and the discussion of

these potentially upsetting topics. However, I related to them, and this also meant that I was able to offer support, and due to my previous research connections I was able to roughly signpost people to their nearest support groups (both physically and the ones existing online for the social media sites that they mentioned using) should they discuss loneliness.

- (3) My lack of a support system regarding Tourette Syndrome means that I have been dealing with traumatic experiences from my teenage years more recently as an adult.

I briefly mentioned my experience of being bullied in school. This was a mixture of physical and emotional, and there were some experiences had that were significantly traumatic for me. However, with psychologist advice to my parents to 'not discuss Tourette Syndrome' and my lack of support system, it meant that I did not do the work to process the trauma caused from experiences such as receiving death threats from anonymous numbers in the early hours of the morning, or of being physically assaulted for 'being a spaz' when walking to a friend's house just 500m away from my own childhood home, as just two examples. (cf. Van der Kolk, 2014, 1994). Going into the research I knew that some possibly triggering topics would come up, and I was correct. There were experiences shared with me surrounding disabled hate crime and traumatic upbringings relating to Tourette Syndrome. It was important for me to acknowledge this positionality as these experiences may be picked up on more by me precisely because it is something that I also have lived experience of.

Whilst there are some limitations and additional difficulties that arise from my aforementioned positionality it is important to acknowledge that in some ways, my distinct positionality here has been a key strength to the project. Having existing networks and engagement within the Tourettic community through my diagnosis of Tourette Syndrome and having conducted previous Tourette Syndrome research had a profound impact on accessing a pool of community members who fit all of the qualifying criteria for involvement in the project. Having not been involved in support services and community groups as a child growing up with Tourette Syndrome I did not have an existing experience

that would influence my reactions to some of the stories that participants of the project shared with me. Ultimately, the strength of my positionality as Tourettic researcher of Tourette Syndrome meant that I was able to sit closely with participant experiences and come to understand them deeply through comparison to my own embodied experiences. As will be revealed in the analysis chapters (particularly in Chapter 5), there is a loneliness that appears to be associated with the Tourettic lifecourse. Additional to any data collection, analysis, and writing-up of this thesis, there is a significant strength to the project that arises from my ability to empathise with participants and to continue facilitating relationship and community building through this project. The lack of exploitative approaches to researching Tourettic communities here feels to be something that somewhat stems from my own positionality, and this is something that adds nuance to the work that comes out of this research, whilst also taking a political stance in line with *nothing about us without us* that fuels the disability movement (Frawley & O'Shea, 2020; Lezzoni & Long-Bellil, 2012; Khedr & Esmanski, 2021; Scotch, 2009).

### **3.5.3 Flexibility**

Flexibility was a fundamental requirement for me throughout this research project for many reasons, the majority of which might fit into previous sections within this chapter. However, in order to bring particular attention to the need for a flexible, bespoke and somewhat iterative approach to researching Tourette Syndrome – with my positionality in particular in mind – this section will explore them in more detail than would have been possible in other chapter sections.

#### **Logistical flexibility**

Practically, I made the decision at the start of the project to be as flexible as possible with timings, dates, and so on particularly surrounding the data collection phase. I wanted to acknowledge that the fact that all participants had many other commitments such as employment, educational commitments or otherwise that ultimately came before their involvement in this project (and rightly so). I had an expectation that there would be some instances whereby people were running late or needing to change when interviews took place, as one example, at short notice. In order to mitigate any risk, I intentionally kept full days free for each interview. Where possible I tried not to arrange any other time-committed appointments, interviews, etc. on the same day as participants' availability for interviews. This ended up being incredibly useful, as

on 11 individual occasions participants requested last minute changes or were significantly late (over 20 minutes) to interviews. Thankfully, all of these participants were still able to be involved in the project and were particularly grateful for my flexibility. In order to be this flexible it was important that I was particularly organised ahead of time for each interview – I would do preparations for interviews a minimum of one day in advance of arranged dates and times. This also gave some leeway for if participants requested an earlier time slot at short notice (which happened 3 times). Not only did this mean that involvement in the project was as little administrative effort as possible for the participants, but I believe that it contributed to the data collection spaces feeling more casual and therefore more comfortable for the sharing of experiences.

Whilst for the most part this approach worked well, it is important to mention that for advisory focus groups this was not possible to rearrange times and be much more flexible. For example, the TIC-Hull advisory focus group was planned to have an additional 2 participants involved, both of whom had forgotten about the call and who were running late. Flexibility in still involving them in the advisory phase in this instance looked like arranging interviews with similar lines of questioning after the focus groups had taken place. I thoroughly believe that all research, particularly when participants are not paid and are having their days disrupted, should take this approach as it is a far more inclusive and accessible approach to research.

### **Disclosure and Researcher Identity**

Aside from the practicalities and logistical considerations of arranging focus groups and interviews, the way that these were conducted required significant flexibility on my part. It was important to take a flexible approach to how much information I shared about myself in each focus group, interview and workshop. The way I made these decisions was with careful planning, but also through simply introducing myself as somebody with a diagnosis of Tourette Syndrome who was conducting PhD level research into Tourette Syndrome. There were some instances where certain elements of my positionality were highlighted or suppressed in order to ensure that the participants felt as comfortable as possible within the session.

One key area in which I suppressed positionality was my religious beliefs. There were multiple instances whereby people shared key concern with religion and the ways that they had been treated in places of worship or by religious groups in the past. When participants opened up to me about this, I felt that it would make the participant uncomfortable if I were to mention that I occasionally attend a non-denominational Christian church and that I would identify under that religion. This is also the case for the times when somebody might mention a religion other than Christianity – I would not want the participant to feel uncomfortable, as I am particularly aware of the oppressive words and actions that the Christian Church has been engaged within previously. However, there was one instance where somebody was specifically talking about their experience of the Christian Church and some negative experiences. They seemed to be struggling to know what words to use when using some jargon relating to Christianity, and in this moment I decided to disclose my religious beliefs and let them know that I had a similar experience. I did not share that I still occasionally attend church, but rather reassured them that I understood the language [heythey](#) were using. This allowed them to continue on with sharing their experience without the hindrance of trying to translate specific jargon.

One area in particular that I was very keen to share was my sexual orientation. As a queer person, I wanted to make it very clear to queer participants that I was also queer, as I wanted to ensure they felt comfortable and safe to share any queer experiences with me. This was of particular importance as some participants appeared a little nervous at first when sharing about anything that might out them as queer. In some instances, where I had previous conversations with people who I knew were queer who participated in the research, I was not concerned about dressing in a more visibly queer way but for those who I was not sure about I felt that I needed to be careful with how I dressed, and although things such as clothes, nail varnish, and so on are not accurate indicators of queerness, I made more of an effort to pass as *straight* when I was not already familiar with the participant. I was flexible with how I presented myself in these situations not only to ensure the comfortability of participants, but also to ensure my own safety in these situations.

### **Linguistic Choices**

Similarly to the clarification of my understanding of certain jargon and language that was previously discussed, there were also linguistic considerations that needed to

be taken into account and a certain level of flexibility was also adopted in this regard. Of particular note is the contrasting language being used to discuss Tourette Syndrome. This is not only the case in academic and healthcare-based spaces, but also within Tourettic communities themselves.

Within this varied language to talk about Tourette Syndrome, there were also varying levels of baseline knowledge about Tourette Syndrome. Part of my flexibility involved talking about Tourette Syndrome in differing ways. Notably, as this thesis will later discuss in more depth, Madge did not know that her *vocal outbursts* were tics and were a part of her Tourette Syndrome diagnosis. I did not feel that it was appropriate to correct her here, and so when referring to vocal tics throughout the rest of the interview with her I was sure to use the language of ‘vocal outbursts’ instead to ensure that we were discussing her experiences in a way that made the most sense to her. Similarly, there were instances where people referred themselves as disabled or neurodiverse in regard to their TS. I was sure to mirror their preferred language when discussing this, which was of particular importance given recent calls for Tourettic people to *make a decision* about which binary category to place themselves within (Ne’eman, 2023). I recently published a response to this call, urging caution and highlighting that the neurodiversity movement was never intended to be a hard-line or produce binary categories of disabled or neurodivergent (Jones, 2023). With this in mind, allowing – and actively respecting – how participants identified and being flexible with the language I used was something I felt I was required to do given my own thoughts on the matter.

Flexibility within the language being used was not only something required within data collection events, but also in the transcription of recorded interviews and focus groups. In particular, I always used the phrase used to refer to Tourette Syndrome that the participant used. For example, if they said ‘Tourette Syndrome’ in full each time, I would echo this. Likewise, if they said ‘Tourettes’, then I would also use this language. This was in an attempt to make the participant feel as comfortable as possible in these research environments. This also carried through into the analysis stage, which is why throughout the analytical chapters in particular you will likely see variation between *Tourette’s*, *Tourette Syndrome* and *Tourettes Syndrome*. The majority of participants wrote one of these in the emails that preceded conducting interviews or focus groups. When this happened, I was sure to use their preferred spelling when discussing their experiences.

When this did not happen, I defaulted to using my own preferred language of *Tourette Syndrome*.

### 3.6 Chapter summary

This chapter addressed the methodological choices and approaches that were adopted in this project and provided some context as to how I came to make these decisions based on my own lived experiences and other onto-epistemological considerations. Concisely, it has outlined my mixed methodological and creative approach to this research project, from ethics to data collection to analysis, and explained my reasoning behind doing so. Specifically, the combination of the methodological aspects of the research outlined in this chapter offered strong, diverse, and emotionally compelling data that was directly relevant to the research questions. Further to this, context has been added surrounding the demographics and creative approaches to research that have informed the analysis to follow. The combination of recruitment and data collection methods proved particularly valuable for the specific focus on adulthood experiences, whilst the analytical techniques used allowed for a deep dive and a close familiarity with the data in a way that was accessible to me as neurodivergent and Tourettic myself.

With this in mind, the following three chapters – Chapter 4, Chapter 5, and Chapter 6 – present the findings and analysis that arose through the approaches outlined in this chapter, drawing upon concepts and approaches raised in Chapter 2 and Chapter 3. Specifically, Chapter 4 addresses research questions 1<sup>14</sup> and 2<sup>15</sup> in discussing the distinctive experiences of public space for Tourettic people through the lens of the *chance encounter*. Chapter 5 concerns research questions 1 and 2 also but taking a deeper dive into digital spaces and the dynamics of Tourette Syndrome support services. Chapter 6 concludes the analytical section of the thesis, particularly focusing on Research Question 3<sup>16</sup>, with a focus on solidarity through particular reflections of the methodological approaches of the zine-making workshop. Following on from the analysis

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<sup>14</sup> RQ 1 is ‘How is the Tourettic experience of public space distinct, and to what extent is Tourette Syndrome a barrier to using public spaces?’

<sup>15</sup> RQ 2 is ‘To what extent does social difference influence the Tourettic experiences of publics, physically and online?’

<sup>16</sup> RQ 3 is ‘How can zine-based methods be used productively in researching the Tourettic experience of public space?’

chapters, Chapter 7 concludes the thesis by developing further the answers to these research questions, before considering research question 4<sup>17</sup>.

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<sup>17</sup> RQ4 is 'What can geographical considerations of a Tourettic point of view contribute in regards to (a) charitable organisations and their practices, and (b) healthcare professionals and their practices?'

## Chapter 4. Chance Encounters: The Social Dynamics of Impulse and its Cycles

### 4.1 Introducing chance encounters

*Kacy finds herself in a supermarket, doing her weekly shopping. The supermarket is a place that particularly triggers her tics; there is something about the flickering strip lighting, the echoing hard floors, and the overwhelm of her senses that causes her to become more ticcy (which is to say that she experiences a greater frequency and severity of tics). She feels the energy build up inside of her, and then she tics loudly, with a vocal outburst. Looking up, she sees a woman in front of her begin to turn her head towards her to look for the source of such disruption. In that moment, Kacy makes the strategic decision to also look behind her, as if also looking for the source of the noise in an attempt to redirect her fellow shopper's gaze away from her. In that moment, the impulsivity of tics associated with Tourette Syndrome created or facilitated the encounter with a fellow shopper. In order to deal with or manage the potential encounter in a way that wouldn't be stressful or anxiety-inducing (and therefore tic-inducing), Kacy put in the split-second decision-making work to create a strategy for managing the encounter.*

Much like Kacy, everybody is managing public space, to some extent. Whether that is through managing your own safety through ensuring awareness of your surroundings, or perhaps through wearing a face covering throughout the COVID-19 pandemic. It might also even be through trying to stop your child from crying loudly and disturbing others when taking them along with you to do the weekly grocery shop. There are strategies that we all put in place as individual people who access and use public spaces to ensure that we don't disturb and that we don't disrupt the flow or cause any unnecessary risk. However, in the case of Tourette Syndrome, the associated aspect of impulse creates additional hidden labour (cf. Scully, 2010) for the aforementioned strategizing that takes place in and around public spaces. People with embodied difference are experiencing public spaces in very different ways and impulsivity shapes that experience even more so for people with Tourette Syndrome. There are strategies specific to the case of TS that are being employed, and this chapter highlights these with particular reference to the influence of impulse and chance encounters, before thinking through the implications of this on overall experience and engagement with public space(s). This chapter seeks to

explore the question of what exactly the influence of impulse is on the Tourettic embodied experience of public space(s), using the chance encounter as a framework through which to work through this.

In the aforementioned experience shared with me by Kacy, the concept of chance encounters is demonstrated. Drawing particularly on the work of de Stefani and Mondada (2018), chance encounters are facilitated by public spaces and the processes that occur within them. These moments of encounter with other affective bodies require work, much of which is distinct in the case of Tourette Syndrome. This could be in de Stefani and Mondada's work that uses the example of a stranger making a specific request of you, or otherwise in the politics and negotiations of split-second decision-making in whether to hold a door open for somebody and what the appropriate amount of time to hold said door open might be. It may also be of significance to here acknowledge the work surrounding *encounters* done by Helen Wilson (2017). In her paper, she outlines how "Encounters allow a focus on the embodied nature of social distinctions and the unpredictable ways in which similarity and difference are negotiated *in the moment*" (2017: 455, my emphasis). Work on encounters is key to this chapter, though this chapter seeks to develop this in thinking through specifically the *chance* encounter, which is not necessarily unpredicted, spectacular, or enchanting (cf. Bennett, 2001), but rather something that can sometimes be predicted and also managed to a certain extent.

Again, we are all managing the encounters we have in public spaces, and creativity in chance encounters comes through the fact that whether strangers, acquaintances, or family members, all humans are affective beings, continuously affecting and being affected. We are all managing the chance encounters that are being produced by the processes occurring in public space. For Kacy, by chance, here she happens to find herself interacting with a stranger in the supermarket. In order to not feel *stared-at* in response to her tic, she makes the split-second decision to look over her shoulder and join the effort to locate the source of the disruptive noise, using this embodied performance of curiosity as her strategy to pass as non-tourettic. She does this to appear in line with normative ideas of how people are expected to interact with and use the supermarket as a public space, in this instance. Where this chance encounter and associated management of it is distinct for the case of Tourette Syndrome, however, is in the impulse associated with Tourette Syndrome as a condition. There are many elements

of Tourette Syndrome that could be referred to as impulsive, with the word *impulse* in particular being used in published medical literature to describe the symptomology of Tourette Syndrome, whether in tics or other so-called behaviours (Mathews et al., 2004; Wright et al., 2012). With this in mind then, it is perhaps key here to understand the sites of production of impulse within the Tourettic body, understanding where they come from, and the processes and factors at play in producing Tourettic impulse, before considering the specific implications for embodied Tourettic experiences of public space(s). From this, the chapter will demonstrate the distinctive ways in which Tourettic impulsivity influences these chance encounters and therefore more generally the experiences had by Tourettic people in public spaces.

#### **4.2 Impulse and the premonitory urge**

The phenomenon of the premonitory urge has been explored within Tourette Syndrome research previously to a great extent, particularly within medical literature. Simply put, the premonitory urge is an internal feeling or physical sensation that precedes a tic of somebody who has a tic disorder such as Tourette Syndrome (Openneer *et al.*, 2020). Whilst not all those who tic experience this, a significant number of participants involved in this research do, and premonitory urges as a topic were raised by the majority of participants, with it being described as an energy of sorts. This energy was likened to a tangible ball that can be shifted and manipulated within the body by some people. It can be done so in ways that allow strategic responses to impulse and the potential chance encounters to follow. The premonitory urge is something that Tourette-researchers express significant interest in from a treatment and quality-of-life perspective. The same significance is echoed through the repeated recurrence of discussions surrounding premonitory urges within interview data. However, the three following accounts of this phenomenon highlight the redirecting of energy as a key aspect of the premonitory urge that is of particular interest when thinking about interaction with public spaces:

Ricki, a young non-binary person living in the South of England, who works with queer support services shared:

*So for me, the majority of my Tourette's isn't felt in the actual tics that I do, but it's in the felt sense of... so I just then felt like a stress in my shoulder that didn't come out as a tic then, but yeah... I always describe it as like a ball of energy and the reason that I can mask my tics is that I can physically move that ball of energy around the body and I can move a hand tic into shoulder tics [...] It's just really awesome that I'm able to feel a*

*tension and know how it's going to interact with and move through my body and a way of feeling my whole sense of self, which I think is really cool.*

- Ricki, Interview 1

Mels, a massage therapist and arts-based practitioner from London similarly outlined that:

*I can move the energy of a tic. For example if I felt the urge to tic in my hand, which would kind of be just the feeling of being ready, almost as if you're waiting to catch a ball or playing a game where someone is going to tap you. I can feel the almost primed-ness of the muscle, and I could move that to a different part of my body, like when I'm massaging and then I'd move that to my head and that would become a tic where I would turn my head to the side rather than [chuckles] anything that the client could feel.*

- Mels, Interview 1

Edward, a grandfather living in one of the southern states of the USA, discussed being thankful for his low-stress museum assistant job. He shared:

*For the most part, no I don't suppress. Like I said, the museum is a very low or extremely low-stress job where my tics don't really come out that much. There's sometimes, and it rarely ever happens, that if I'm at work or in a store and I feel a major tic coming on, I channel it into a much smaller one, like a hand-shake or a finger-wagging, or something like that.*

- Edward, Interview 1

The examples above highlight the processes and the experience of not controlling but perhaps influencing this impulsive Tourettic almost-movement, which some but not all participants were able to do. The strategy of *redirecting* or *channelling* the premonitory urge associated with a significant and more disruptive tic into something else seemed only to be made possible through this pre-tic awareness of a tic to come. Here, the ability to move this *ball of energy* or *urge* around, or to redirect it, was discussed positively. It was referred to as a reason that the participants in question here were able to mask their symptoms of Tourette Syndrome, such as through Mels' account of trying not to allow her massage clients to feel her hands tic during a session; or with Ricki's description of the acknowledgement and controlling of premonitory urges as *the reason* that they were able to mask, and perhaps even pass as non-Tourettic in some instances. There is additional,

hidden Tourettic labour taking place in the redirection of these tics. Edward directly links this into ideas of suppressing tics, considering the very direction of these premonitory urges into less noticeable or less disruptive tics. The extracts here demonstrate a certain level of control, then, over the impulsive affective events that act as inflections of the curvature of a chance encounter as per the Tourettic application of the elasticity of almost movement.

Manning (2009) explains that during a couple's dance, notably the tango, movement occurs in relation to the partner. The leader doesn't control, as such, but rather guides. The lead provides a preacceleration of almost-movement that is sensed by the other dancing affective body, and the dancer who is being *led* moves *in response* to this almost-movement. As a result, the two dancing bodies move together gracefully, and with ease. Each movement is prefaced with this preaccelerative almost-movement that propels it forward, and at the peak of each movement is where the elasticity of almost comes into play. These elastic points are not the same – they are not absolute repetition – but are similar enough to be recognized as a pattern, further accelerating the movement-as-one of the dancing bodies. The chance encounters, or energies and affective events yet to happen, influence movement through space. If we conceptualise tics as inflections in this regard, we can make direct links to the relevance of tics and suppression in influencing how public space is navigated. This is significant in thinking about the ways in which the impulsive element of the premonitory urge influences Tourettic embodied experiences had in public spaces, both prior to and during a particular moment or event, per se.

Sutherland Owens *et al.*'s (2011) work on sensory gating and the premonitory urge used structured and semi-structured interviews based around various tic severity scales and questioned specific symptom severity that was related to premonitory urge. The paper showed that within their data set Tourettic people experience higher levels of perceptual modulation, distractibility, over-inclusion (lower threshold of perception) and fatigue-stress vulnerability. In short, what these researchers suggest here is that the occurrence of premonitory urges has a significant influence on the Tourettic experience. The importance of the premonitory urge in influencing experiences had by Tourettic people is highlighted by the previous participant accounts, along with the fact that the premonitory urge as a topic of discussion in interviews and focus groups was constant

throughout the large majority of the collected data. Practically, the embodied effect of the premonitory urge can surface in a multitude of ways, as demonstrated by multiple participant accounts from this project's sample.

Charles, a man in his late fifties living in the North of England, spoke to me about the various ways in which he minimises the intensity of premonitory urges and discomforts. Thinking about the workplace, Charles shared with me that he feels extremely frustrated by the need to try and 'control' his working environment to try and minimise the premonitory urges that he experiences. For him, doing so looks like taking regular sensory breaks and having to request specific workplace adjustments, which is something he suggested that he is not necessarily very comfortable doing. He didn't specify the reasons for this, but implied that it was more related to a sense of self and perhaps a hesitancy as to not knowing how his employer might react. He stated that he is constantly trying to minimise the distractions caused by premonitory urges so that he can simply *get on* with the work he needs to do. This management of environment goes beyond the workplace however, as he showed me a pair of headphones that he used on a daily basis to block out the triggering sound of road traffic, as one example (Charles, Interview 1). Additionally, Pete, a technology teacher from East Yorkshire, shared with me his experience of premonitory urges and the feeling he experiences prior to a tic where he might tap somebody on the shoulder. He knows the tic is coming, and in some instances that there is nothing he can do to stop it. After the tic happens, he shared with me about the immediate return of the impulsive urge to do it again following the surfacing of not only that specific tic, but the majority of others as well (Pete, Interview 1).

Within these experiences shared, there seems to be an underlying uncomfortability<sup>18</sup> that is experienced regarding premonitory urges. This uncomfortability is significant in influencing the ways in which people attempt to navigate public spaces (or manage encounters within them). Internal sensations interact with external possibilities. What might my colleagues think of me if I tic loudly? What is the least disruptive way I can redirect this tic? What is the best option? Questions such as these influence the way that people respond to premonitory urges. This could be in Pete's knowledge of a forthcoming tic and being able to plan accordingly; in [Charles'Charles'](#)<sup>2</sup>

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<sup>18</sup> The word 'uncomfortability' has been used here as it encapsulates not only pain, distress and irritation, but also the unease and anxiety of that 'discomfort' implies.

attempt to remove sensory engagements from the environment that assist in the strengthening of these urges; or otherwise. For those Tourettic people who experience premonitory urges then, there is a sort of uncomfortability that underwrites every moment and every interaction. Milly-Anne, a student from Liverpool, spoke clearly to this, in saying that her “Tourette’s is very tied to feeling uncomfortable,” noting that if she was uncomfortable she found herself being more nervous, which in turn increased the severity and frequency of her tics (Milly-Anne, Interview 1).

Not only do the Tourettic premonitory urges influence direct interaction with space, through taking a step away for a sensory break, or through the use of noise-cancelling headphones to reduce triggers, but there are also emotional elements to consider too. These emotional elements associated with premonitory urges and their influence over interaction with space are important to acknowledge in thinking about impulse. Premonitory urges and tourettic uncomfortability, as per Pete’s aforementioned experience, do not always disappear following a tic; the discomfort can remain within one’s body. This can be an extremely stressful and anxiety-inducing experience for many. For Bella, a wheelchair-using trans woman who is an LGBT and Tourette Syndrome advocate living in the North of England, the overwhelm or ‘overload’ experienced as a part of premonitory urges was extremely significant. In one interview, she stated:

*...someone stares at you and you instantly become kind of watching over your shoulder and being on edge, and you know it’s there so you keep watching to see if they’re staring, which makes it worse. Then you start getting tense and ticcing more, and then other people start looking more and it’s a constant, brutal cycle. [The other day] I was in TK-Maxx. For some reason there were too many people and I’m normally fine in that one... I know the shop like the back of my hand, and it just... something got too much and I had to get out of there. I never do that! Something just got- and I had overload. And then there was a lovely lady in a- well she might have been lovely, she might have been a twat I don’t know – in a hijab. But there of course I’m thinking “Suppress, suppress, suppress” ‘cos it was going to be “ISIS” or something [that I ticced]. I pushed myself away, and get round the corner and what do I see next? Another woman in a hijab! And I was like “oh for fuck- will life give me a break? Will life let me be nice to people and respect people?” No it won’t. And it got so overwhelming but because I’m in my chair, the clothes rails are taller than me. It feels like you’re in a maze as you can’t see over, and it was really difficult. That was a prime example of overload, just like that.*

[Bella, Interview 2]

Here, we can see that Bella has an awareness of what specific tics might be triggered by a specific circumstance, or chance encounter, through the premonitory urges that she experiences. In this account, she attempts to remove herself from the impulse-inducing scenario, only to find herself in another, which causes her to feel overwhelmed. Bella also explored this within the zine workshop, where she drew the image shown in *Figure 1*. This figure shows an account of Bella, using her wheelchair, and experiencing this overwhelm/overload within a shop, where people are staring at her, noises are triggering her, and so on. Evidently, this impulsivity associated with the Tourette premonitory urge can cause a sort of sensory overload when the chance encounter in question is unable to be managed<sup>19</sup>, and there are no strategies that can be implemented for adequately controlling the situation. This is significant and proved to be an incredibly important way in which participants within the project understood their own experiences within public space. The premonitory urge and its associated uncomfortability, then, underwrites not only the material interactions with public spaces, but also the immaterial, emotional elements of sense-making that play a role in the embodied experiences of public spaces.



Figure 1: A piece that Bella created within the zine workshop, exploring her experience of being in public space through using the example of her experience of 'overload' whilst in a shop.

<sup>19</sup> In referring to unmanageable chance encounters here, I am referring to instances where the internal feeling of the premonitory urge is too strong, whereby a tic might not be able to be suppressed or redirected into something more subtle.

Further to uncomfortability of premonitory urges being instrumental in the way that Tourettic people understand their own experiences, it is also a way in which some Tourettic people refer to in attempting to communicate their experiences to those who do not experience tics. For example, in an interview early on in the project, Bella shared with me how when explaining TS to non-tourettics, she would compare the moments preceding a given tic that she experiences premonitory urges for to the urge or the build up to a sneeze, because for her it was the closest thing that she feels is comprehensible to those who do not experience tics (Bella, Interview 1). The language of urge wasn't used by all participants, but the significant majority were able to suppress at least some of their tics, which implies understanding of this feeling of urge and this conscious attempt to remain in the moment of almost-movement that precedes a tic. On a personal note, using the simile of *like-a-sneeze* is also the way that I myself as a Tourettic person have described the feeling of tics and the build up to them/their associated premonitory urge to people in the past, and has even been used as a metaphor adopted by social media content creators (cf. gamerner157, 2022), the NHS (2021) and researchers (Box, 2008; Hartman, 2017; Turner & Turner, 2009) alike. The way that common experiences such as the urge to sneeze was used to conceptualise the premonitory urge by Tourettic people for non-Tourettics in particular highlights the sheer everyday commonality/mundanity of the experiences to an extent that suggests the significance of premonitory urges and associated uncomfortability on everyday life-course for Tourettic people. If the influence of the premonitory urges and almost-movement is of significance at such a macro scale for Tourettics, there is no doubt that the influence of premonitory urges and almost-movement is significant in influencing the ways in which people use public spaces. This significance is different for everybody, with variation in what it looks like practically on an individual, bodily scale.

The premonitory urge may be significant for Tourettic people who experience them, but the way this manifests for people differs; the constant discomfort *looks* different to different people, and the discomfort can also have different impacts. For Ricki, the premonitory urge was significant in allowing them to feel their "whole sense of self" (securing them in their identity and in knowing who they are), being key in the way they understand themselves and the world around them. For Mels, premonitory urges

influence the way she interacts with massage clients, whereby she is required<sup>20</sup> to put energy into not only her job, but also in directing premonitory urge and impulse to specific parts of the body that would not disrupt her client's massage. Similarly, Edward shared how he redirects any 'major tic' into more subtle tics during the working day, with a finger-wag being preferable to a loud, vocal outburst that might disrupt the silence of the museum. For Charles, the uncomfortability of premonitory urges is significant in influencing even what he wears when out in public, in this instance using noise-cancelling headphones to try and keep the loud road traffic noise that increases the severity of premonitory urges at bay. Bella's premonitory urges were significant in her decision to begin moving away from, and continue avoiding, a woman in a shop who happened to be wearing a hijab, because she could feel coprolalic tics relating to race and racial stereotype beginning to surface. The urges changed even what areas of the shop she went to or skipped past and didn't engage with in order to find some kind of relative safety from the triggering of these urges. This *safety* encompasses safety from possible social penalty of Bella ticing "ISIS" for example, or the physical risk of having significant motor tics that might cause Charles to lose his balance as he walks on the path next to a busy road, as two examples.

Evidently, the ways in which premonitory urges happen; the impacts on use of public space; and ways in which people manage them differ on this bodily scale. However, the creation of a constant, underwriting discomfort for Tourettic interaction with and embodied experience of public space remains true for all the Tourettic people who are experiencing premonitory urges. These premonitory urges, in turn, influence chance encounters. Take the example of Bella avoiding the woman who was wearing a hijab – if Bella had not acted upon her *feeling* of the premonitory urge, she said herself that she might tic "ISIS" towards the woman. This would have resulted in the redirection of the encounter that Bella had with public space in that moment. The woman may have stared at her, or perhaps even approached her to express disgust for the outburst. Even further to this, Bella was in part working to manage the risk for the woman who was wearing the hijab, in not wanting the woman to experience what might be perceived as a racist attack. On the other hand however, she may have been familiar with Tourette Syndrome, meaning

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<sup>20</sup> When I use the language of being 'required' to redirect tics, energy, and so on here I am referring to being required to put the work in to do this in order to feel comfortable, and to minimise the risk of possible negative encounters that might occur should certain tics happen in certain contexts.

she may have glanced over, smiled, and carried on with her shopping. However, the assumed *risk* of what that chance encounter could have been was too high, hence Bella's decision to remove herself from the situation. These premonitory urges are significant enough to encourage Tourettic strategic responses to them, in turn influencing the direction of encounters had within these public spaces. Premonitory urge plays a significant part in experiencing public spaces for those who experience them, in the sense that strategies are implemented to avoid physical and social *risk* or *penalty* that might occur in a negative encounter being facilitated partly through ticcing. Whilst a significant part of the tourettic experience, perhaps there is also scope here to consider how this also applies for the wider, non-Tourettic population. Again, everybody is navigating and strategizing in one way or another when in public spaces. The distinction here for Tourette Syndrome comes from tics and their premonitory urges, and in many instances this desire to control the risk experienced by others is something that Tourettic people are working towards. It is not only the chance encounters relating to the self that come into play here, but also that of others and the labour that comes with doing so. These encounters between affective bodies work to encourage impulse and tics in distinct pockets, providing a host of opportunities.

#### **4.3 Pockets of opportunity for impulse**

The previously discussed examples and participant accounts could be said to all occur within pockets of opportunity. By *pockets of opportunity*, I mean to refer the moment in which impulse can occur, or for a response to Tourettic impulse (such as a tic) either by the Tourettic person themselves or an external body. This can be positive or negative in its categorisation. The premonitory urge, perhaps, could be considered a pocket of opportunity in itself, in that it gives a moment for the Tourettic person to respond, either in the redirection of this Tourettic ball of energy, as mentioned by Mels and Ricki, or in providing moments of opportunity in which to realise key triggers like with Charles. Further to this, these pockets of opportunity can be linked to ideas of a sense-of-place (Turner & Turner, 2009) on a micro scale, that link into subcategories of Tourettic impulse that will be discussed next through considering a sense of anonymity in place, the proximity to so-called anonymous-feeling places, sensory engagements, and socialities that create this sense of anonymity within public spaces.

#### 4.3.1 Sense of place; sense of anonymity

Within the data collected, the participants largely stated that success, to them, in public spaces was being able to retain a sense of anonymity. Participants frequently mentioned that being ‘noticed’ was a significant, and frustrating, part of their experience of being Tourettic and of occupying public spaces. Kacy shared that she enjoys the anonymity she experiences in public spaces as people do not know she has Tourette Syndrome. The worry for her comes in that if she is with somebody who knows her, they will disclose on her behalf without consent if she tics. This means that she will not be able to implement the strategy of looking over her shoulder to perform the act of looking for the source of the noise, as previously discussed. Whilst the accounts of this desired anonymity were varied, they very much express that anonymity is key to assumed success in public spaces, which mirrors academic literature regarding anonymity and public space (cf. Kwangmin & Chajoong, 2017; Matthews, 2010; Morgan & Newton, 2004). For the Tourettic people who participated in this research, a sense of anonymity is key to successful and comfortable use of and interaction with public space(s). This sense of anonymity or privacy of sorts is produced in different places through a multitude of differing, intersecting processes. This section particularly considers these, highlighting the relevance of ‘pockets of opportunity’ for inquiry into Tourettic experiences of public space.

For some, a sense of anonymity was something that allowed them to not be disrupted by their tics. An extract from collaborative zine *Tic Tic Boom!*, written by Porkchop reads:

*In public places it can be stressful with people staring and saying stuff and it makes me tics worse, but when I'm in public places I know [with] the people [I know] I can be me with a little bit of tics*

- Porkchop, extract from *Tic Tic Boom!*

Porkchop is a young adult living in the Yorkshire area, who enjoys drawing and helping out at his local Tourette Syndrome awareness charity’s main hub. He does not work due to his diagnoses and disabilities and was very involved in assisting in the initial planning phases for this project. For Porkchop, he can find public places quite stressful due to the expected encounters with strangers who he expects to stare at him when he

tics, which makes him anxious in turn resulting in a greater frequency and severity of tics. Porkchop's desire for anonymity in public spaces means that he is anxious about being in public on his own; his management strategy, in this instance, is to either avoid public spaces or to only go to familiar places with people who are already aware of his diagnosis of Tourette Syndrome, and who might be more familiar with his more common tics. By feeling more *at ease*, Porkchop here expresses how his tics are less disruptive and stress-inducing for him in instances where his sense of anonymity remains intact, not shattered by the stares of a stranger.

Whilst for Porkchop a sense of anonymity can reduce tics through increased comfortability, for others this sense of anonymity has different effects. Darren is a young man living in a rural village in the North of England, who enjoys travelling around the UK and visiting new cities. When talking about places in which he experienced significantly more tics, Darren shared that he tics in places where he feels a sense of anonymity, then said:

*... one [place] that would be a good example is lifts. I'm quite fine in lifts, but I feel the urge to tic in lifts whether it's empty or not – that's my free space [where I have enough privacy to let tics out]*

- Darren, Interview 1

The experience shared here of increased tics and Tourettic urges being more *severe* in spaces associated with privacy by participants such as Darren highlighted how a sense of anonymity is key in thinking through these pockets of opportunity for Tourettic people. A sense of anonymity was associated with the ability to *give in* to the premonitory urges and feeling comfortable to stop suppressing by the significant majority of participants. For Darren, he shared how the lift as a symbol of anonymity resulted in him experiencing more significant premonitory urges, where he struggled to suppress as much as his baseline ability might allow for. He attributed this to the fact that the elevator as a space feels private. His body responds to this sense of anonymity/privacy through increased ticcing, both in frequency and severity, whether or not there are others in the elevator with him. Whilst the effects of this sense of anonymity are varied, for both Porkchop and Darren we can see that sense-of-place is extremely significant in determining this sense of anonymity – for Darren, the elevator is a place he

subconsciously feels safer to allow tics to surface (whether he wants to or not), and for Porkchop his wider mobility is influenced in thinking about his preference of going to places he is familiar with, with people he knows, as he feels more anonymous in those spaces. No matter which example you focus on here, it would appear these spaces that reinforce feelings of anonymity are key in offering pockets of opportunity for impulse to manifest, in the case of Darren, or an opportunity for lesser disruption, in the case of Porkchop.

The relevance of anonymous places is significant to the extent that one participant - Leonard, a young adult working as a postdoctoral researcher from the Netherlands - shared the relevance of even the proximity to spaces that foster this sense of anonymity or privacy in determining the severity and general manifestations of Tourettic impulse. Leonard discusses the somewhat subconscious suppression of tics throughout his working day, and how as he gets further along his commute home, and therefore closer to his home, he would experience tics more. By thinking through this idea, I began to reflect on my own experiences as somebody with Tourette Syndrome:

*On my drive home today from Hull, I realised that I was experiencing what I had been chatting with Leonard about – I stopped for a coffee on the way home and wasn't experiencing many tics. The longer I drove and the closer I got to the privacy of my own home, the more my tics worsened – the urges growing stronger and harder to control as I came closer to the end of my journey*

- Researcher, research diary entry

Sense-of-place and its relevance has been discussed at length within previous geographical literature. This section specifically highlights the extent to which places of which privacy and feelings of relative anonymity (and therefore safety) have an influence over the embodied experiences happening in public spaces. The influence of places that retain a sense-of-anonymity is so great in the instance of Tourette Syndrome that for some, myself included, the person does not need to be in a specific place to experience the effects of said *place* on their Tourettic impulses, both in relation to tics and otherwise. The impact the aforementioned instances and processes can have on embodied experiences is greatly varied. Perhaps a sense of anonymity allows you to find a pocket of opportunity to tic in without being exposed; perhaps that same sense of anonymity relaxes people and so they experience less tics and therefore use less energy to suppress.

Where anonymity is implied, the risks feel lesser. This pocket of opportunity offers an affordance (Bruineberg & Rietveld, 2014), so to speak, for continued sense of anonymity.

#### **4.3.2 Sensory and social interactions as anonymising processes**

If we consider the importance of a sense-of-place and previous encounters within said space that influence sense-of-anonymity, it is vital to consider the sensory engagements and interactions that we experience in public spaces. Tics can often be sensory in nature; specific sounds, smells, textures (and so on) can influence Tourettic impulse. With this in mind, these pockets of opportunity provided by a sense of anonymity were not solely on the scale of buildings or physical spaces with material confines such as an elevator or a house, but were described as fluid spaces, moments or opportunities to retain a sense of anonymity. They could be long, stretched-out moments of relative anonymity whilst on holiday, as discussed by Adrian when discussing the joys of being somewhere where nobody knows you and of being around people you will likely never see again (Adrian, Interview 1). Alternatively, this could be even in the significantly smaller scale in the creation of movements or sounds by people, objects or other organisms found within the everyday, and within public spaces.

*[Sometimes there might be] a loud sound or even if you just walk somewhere and the door opens and you know that the door will close at a particular kind of moment – you just kind of say [or tic] something right in the moment when a door bangs, and there are these little in-between moments where there is not so much of a sense of being heard, right? Or of being caught or seen as different... They're moments you can use in a sense. These kinds of loopholes do exist and they tend to be used to tic in*

- Leonard, Interview 1

What Leonard highlights here is the influence that affect and affective events have over the production and navigation of these pockets of opportunity. A sound might be productive of a moment in which to allow a suppressed tic to surface; a moment for the Tourettic person to *give in* to the impulse they experience. Looking back at some of the aforementioned examples, they also demonstrate this. Returning to the example of Kacy who experiences a vocal tic and turns behind her to try and redirect any potential stares beyond her, also acting as if she was looking for the source of the sound – this comes in a response to somebody else turning and directing their gaze towards the rough location of the sound's source. Perhaps this is also seen in Tabitha's discussion of how the actions of others that she may be in a given public space which allow for these pockets of

opportunity whereby impulse can surface. Whether in the chance to actively not suppress tics or in offering the potential for a moment of relief from said urges caused by the stressors of trying to remain unseen or anonymous in her diagnostic status as a Tourette person, whereby people aren't wondering what is *wrong* with her, as such:

*You know, and I've jostled someone with a cucumber, and I threw a cauliflower at a lady before and I've [...] done these things and it's like you're just kind of stuck in that space [...] I find [supermarkets] especially hard on my own, without that social buffer of someone being like "It's fine", or just of being able to look at my friend instead of the person I've just accosted [...] or having someone else just being able to explain for me what's going on*

- Tabitha, Interview 1

Within this extract from an interview with Tabitha, however, a particularly interesting idea of being 'stuck' in these spaces presents itself. In these moments, Tabitha relies on somebody else who she is familiar with to act as a so-called 'social buffer', that perhaps softens the blow or the responsibility for how one reacts or responds to these pockets of opportunity. Were Tabitha to be alone in the instance where she threw a cauliflower at somebody, perhaps that pressure of having to decide whether to disclose her diagnosis of Tourette Syndrome, along with how exactly to describe it as to avoid further confrontation and negative outcomes of this opportune moment would have felt more significant – the stakes would have felt higher, so to speak. A social buffer here, or the act of being in public spaces with others, is evidently a significant element to consider when thinking about the creations of these pockets of opportunity. After all, if a stranger can open a door and provide an opportune moment of noise with the door closing for a vocal tic to be released and go unnoticed, for example, then the embodied experiences and the pockets of opportunity influencing them will be significantly influenced by the other affective bodies within that space.

Bodies and the affective events in which they engage that might produce sound or movement can also act as a social buffer of sorts, such as per Tabitha's phrasing/account of this. In her interview, Tabitha also stated:

*[I went on a TS exchange and] it's almost like there's safety in numbers. You can't be embarrassed because you are 1 of 50 people [ticcing... When you're out with others who*

*do not have Tourette's, you're] a lot more noticeable that when you're out with people with Tourette's, 'cos you're not one noisy person in a crowd of norms...*

- Tabitha, Interview 1

Here, Tabitha is referring to an instance where she found herself taking part in an international Tourette Syndrome exchange. A large UK TS-awareness charity paired up with another large charity based in the Netherlands to promote community building amongst Tourettic adults. For Tabitha, when using public spaces with the large group of 50 Tourettic people there was less of a sense of anxiety and more of a sense of the retaining of anonymity. She stated that this sense of anonymity came from feeling as if when there are so many people ticcing and being disruptive, there's 'no chance' that others do not know what is 'going on'; the tics in these instances seek to draw attention to the wider group, but not to individuals within the group per se. There appears to be an anonymising social buffer in instances such as these that result in people feeling more comfortable and able to use public space. Tabitha compares this directly to the experience of being in and around public spaces with other known individuals who do not have Tourette Syndrome.

The key differences here can be seen when considering the removal of anonymity through *required* or *forced* disclosure of a person's diagnosis of Tourette Syndrome. Take for example the instance where Tabitha speaks of a social buffer whereby a known friend or family member can distract the attention away from her by disclosing or explaining to the onlooker what the situation is regarding Tabitha's diagnosis, how she had no control over whether or not she threw the cauliflower, etc. In this scenario, this social buffer doesn't help to retain a sense-of-anonymity, but puts up a protective imagined barrier of safety, as such, through this redirection of attention through conversation, disclosure-by-proxy, etc. However, in the instance where a large group of 50 people who all have Tourette Syndrome are ticcing where Tabitha says "you can't be embarrassed". This is the key difference. Tabitha refers to people being unable to not understand what is going on in a group of tourettics that large, and so disclosure is not *required*. Disclosure is not needed to be used as a management strategy to soften the blow, or to make an encounter less jarring, so to speak. The situation is too big, too hard for others to manage and so becomes something that people have no choice but to *let slide* in the case of the group of

50 Tourettic people. It appears here that disclosure is somewhat synonymous with embarrassment when implementing it as a management strategy, either being implemented by the Tourettic person themselves or those known people who they are navigating through a space with.

There has been work published that explore the politics of disclosure and explanation, particularly surrounding autism and phrases such as 'I'm not naughty, I'm autistic' that are often found on badges, t-shirts and other such wearable items (Jeffries, 2022). This links in with concept of stigma that I refer to here in that there are stigmatised understandings of various disabilities and neurodivergent conditions, that can be perpetuated through phrases and branding such as this. So perhaps the hesitancy of engaging with these kinds of TS specific disclosures in this way by the participants is considered to individualise and further pathologise the tourettic body in a way that publicly being in a large group of tourettic people doesn't. The use of t-shirts and the likes with slogans on might be a form of buffer but is not a preferred disclosure-based management strategy of chance encounters for the participants of this project. This is likely due to the fact that these kinds of t-shirt slogan disclosures are often facilitated by the parents of disabled children, who encourage their children to wear these clothes. When we move past the infantilisation of disabled adult Tourettic people, these preferences change.

Social buffering goes beyond solely disclosure, however. The idea of social buffering via the presence of other, known, people sharing or simultaneously using a given public space was further discussed by other participants within the project. For example, Lizzie, a sixth-form student from the North-East of England stated that:

*I get a lot of anxiety [about my tics] going into public spaces, and the only time I kind of feel like I can positively tackle them is when I've got my family with me or my partner, because they're kind of like my protective bubble*

- Lizzie, Interview 1

Feelings of anxiety, stress and embarrassment are significant in influencing the experiences that somebody has when using public spaces. As per the previous discussion of the influence of affective events on the elasticity of almost movement, they play a key part in influencing the flows and rhythms of embodied experiences to follow;

that is to say that these affective emotions and feelings of anxiety, stress and embarrassment are key in influencing the narrative arc, as such, of the chance encounter yet to be had. With this in mind, the interview extracts included above demonstrate the extent to which the presence of known and trusted others such as friends, family and partners influence their comfortability, and the extent to which this determines whether or not they feel these affective emotions of anxiety, stress and embarrassment that are likely to increase a Tourettic individual's tics, both in severity and frequency (and therefore also in levels of premonitory urge experienced/felt). All of these things work together to influence the impulsivity felt/experienced by the Tourettic body in question, in turn determining the embodied experiences had.

Experiences of anxiety, stress, and embarrassment and their influence over the associated negative experiences of impulse had in public spaces then further change the Tourettic individual's future interactions and modes of navigation in and through public spaces in the sense that they might avoid places without the accompaniment of familiar others. For example, Stacey – a musical theatre student from the North of England – outlines how she struggles when required to queue in public spaces due to Tourette Syndrome, and so where possible she will try to be out in public with her mother. The social, affective dynamic of waiting in queues as described by Jones as “*matte* and muted or dulled is made visible through the stillness of people in the queues” (Jones, 2022: 9). Similar to the aforementioned pockets of opportunity for tics, the visibly *matte* social dynamic of the queue as described by Jones here is an example of how queues may act as a pocket of opportunity for tics (and therefore also opportunity for negative encounters, as the following section will address). The impulsive urge to *fill* this *matte* space is what actively produces Stacey's uncomfotability in these situations. Resultantly, when required to queue, Stacey mentions how her mother might stay in the queue and that Stacey herself will leave to walk around and get some space and she discusses how this helps to minimise her tics. Not only does this relate to the ways in which past experiences of impulse in public space change the ways that somebody navigates it, but this is significant in the way that there is an opportunity to respond to impulse in public space that is somewhat facilitated by Stacey's very being with her mother in the aforementioned queue. Having somebody to explain, to act in a carer capacity, or to act as this *social buffer* of sorts is evidently influencing not only the impulses experienced themselves, but

the ways in which those impulses are able to be creatively responded to or negotiated. This is much like in the aforementioned example of Charles taking a step away from his workplace to provide him with space and to reduce triggers - something which has been facilitated through an awareness of Tourette Syndrome by his line manager within his place of work.

#### 4.3.3 Pockets of opportunity and threat

Whilst there is an opportunity for the presence of others to act as a social buffer in a facilitative or care-giving manner for tourettic people within public spaces, there is also the potential for Tourettic triggers of greater impulse by those very same *known* people. Heightened experiences of impulse can be triggered by other people whether or not they are tourettic themselves. This was a theme that was raised repeatedly throughout the project:

*[...] a lot of my tics come from [...] sort of implied pressure when I go to, say, my partner's family's house or flat, or even out for a birthday meal. I will end up suppressing tics*

- Joey, Interview 1

*I went to a Jewish school when I was younger [...] and obviously lots of my friends had bar mitzvahs and I hated going to bar mitzvahs [...] it's quite intense in that everyone is sitting at tables and when you're all at tables people are looking at you no matter what*

- Adrian, Interview 1

These two extracts from interviews demonstrate how unintentional aspects of sociality and social difference played a role in determining felt Tourettic impulse. The sense of place produced through familial expectations placed on Joey, for example, led him to spend more effort suppressing his tics and fighting to not allow impulse to manifest; for Adrian, simply the idea that a person's gaze might be directed towards him made him anxious and therefore tic more. Although not spoken explicitly, it was implied by tonality within these two interviews that the other individuals being discussed did not have a diagnosis of Tourette Syndrome, and so the suggested social differencing – or othering – that was occurring through even *known* non-Tourettic others was influencing the ways in which people experienced impulse. For Joey, he mentioned that this forced suppression of sorts led to him sweating a lot, making him even more uncomfortable, and

having a cyclical effect whereby he would tic more, or at least would have a harder time attempting to suppress the tics. For Adrian, the context given prior to the aforementioned quotation was that I had prompted discussion by asking him about public spaces that he felt uncomfortable within or that he tended to *avoid* (to use the exact phrasing of my questioning) where the reasons were linked in with his experience of Tourette Syndrome. As Adrian was 27 years old at the time of interviewing, the fact that he stated that he avoids more formal, sit-down meal-styled events similar to what he remembers of bar mitzvahs he attended as a child is significant. It demonstrates that impulse and Adrian's experience of impulse when using public spaces have long lasting impacts on not only the ways in which impulse changes how a Tourette might use public spaces, but also the kinds of spaces they might actively avoid or *not use*. It would appear that the combined formality of the bar mitzvahs Adrian attended as a child and the material aspect of being placed around a circular table, all eyes gazing towards a central point, came together to generate a legacy significant enough to have impact many years down the line.

Avoiding places came up multiple times throughout the course of the project. One case that stood out in particular was that described by River, a young-adult trans man living in the south of England. In the interview, the specific language of the avoidance of places came up within my questioning, and this resulted in River sharing with me that one of the *kinds* of places he tends to avoid are places of worship. When asked to elaborate, he said:

*For context, I have left church and Christianity. I was brought up as a Christian; decided to stop because I was queer; and then was welcomed back as a queer person into a different church. But I've decided to leave the church because of the people. Not because of my faith or my religion, but because of the people and their responses to me being queer but also to me having Tourette's. People think I'm possessed; they think they can come over and pray for me to be healed without asking; or [that I need to be] purified. They'll touch me without permission and it's just like "Ah, get away!"*

- River, Interview 1

Here, River shares that his Tourette Syndrome was a significant part of why he left the church, and shared that whilst some churches had accommodated him by allowing a separate room in which the church service would be streamed to, away from a large group, that the key issue for him here was that "I feel so unsafe in a church that I have to put myself in a box, in a room separate from everyone else in order to feel safe" (River, Interview 1). Evidently, the *place of worship* as a pocket or a *genre* of place, as such, is a

pocket of opportunity for negative chance encounters – this could be referred to as a pocket of threat.

On a similar note, Sugar Tits shared with me that whilst there aren't any places that she necessarily avoids, that some days these so-called pockets of threat are overwhelming:

*Sometimes I don't even go out the house because I can't deal. Me having a day off and just pottering around the house involves me not even going to the shop when I'm out of milk and I'm out of food, and I'm like "I don't want to know anyone today"*

- Sugar Tits, Interview 1

Evidently, for Sugar Tits any kind of public space (that is to say spaces outside of the privacy of her own home) become 'too much' to deal with; there were worries expressed by Sugar Tits in her interview about the looks and interactions with others that she might have if she is to visit any public space that make it *not worth the stress*. Whether in River's concerns over places of worship, or Sugar Tits' concerns over any and all public spaces on days when her tics are more severe, impulse and impulse-influenced experiences of previous (negative) chance encounters are significant. Experiences of public space within these chance encounters linger; they not only have impact in making the Tourette experience of public space itself distinct, but also over which public spaces continue to be experienced.

A lot of discussion over the avoidance of certain places/spaces was as a result of intersecting identities amongst participants. For example, as aforementioned River outlined his identity as a transgender man also played a part in his decision to leave the church. However, in this discussion he also shared with me that his identity as queer might lead him to be surrounded by other queer people in public spaces such as an LGBT+ pride event, which had disruptive effects in itself:

*I thoroughly enjoyed Pride, but my tics during Pride ... didn't allow me to enjoy it fully [... I had tics that were] calling people slurs and yelling slurs basically. I was in the parade on a float and I was trying so hard not to be like [\*points to different places\*] "You're a fag; you're a fag; you're a fag". Oh my gosh it was awful [\*sighs\*] but yeah, I love Pride but anywhere there's a marginalized community that I'm a part of or not a part of – it doesn't matter because my tics don't care if I'm racist or not – will just... yeah... some of them are so awful. Some of them are ones that I really hate.*

[River, Interview 1]

As outlined, River experienced a greater number of coprolalia tics that were queer-phobic slurs when at a Pride event, where he was partly celebrating his own identity as trans. Whilst this was evidently stressful for him, it did not stop him from accessing a specific space in this instance. However, there is clearly potential for negative encounters in these spaces. As a trans man, River said that sometimes he passes for cis. This means that in some instances, if River was to tic a transphobic slur at an event such as Trans Pride, he would likely feel more inclined to then out himself as trans as a mediation strategy for navigating through said chance encounter.

When interviewing Nesta, a mixed race young man living in the midlands, he outlined that he was concerned about exposing himself to the triggering language of tics that featured racial slurs that he might hear at in-person Tourette Syndrome support services. He said:

*I think I'm sometimes a bit apprehensive about going to groups with people with Tourette's because I don't know what tics they'll have and I don't want... even if I know that it's a tic, I don't really want to hear racial slurs and things like that*

- Nesta, Interview 1

In short, Nesta avoids support groups for people with Tourette Syndrome because he does not feel comfortable with the possibility of a chance encounter that features racial slurs, regardless of whether they are tics or not. It seems as if he is aware of the ways in which Tourette Syndrome works, as somebody with a diagnosis himself, in that those with coprolalia often experience tics directed towards global majority ethnic or social minority groups, as River also stated. Nesta's identities as Tourettic and as mixed black-Caribbean and Asian intersect and interact in interesting ways that results in his avoidance of this particular public spaces. In speaking on intersectionality, identity and society, Appiah writes that "We make up selves from a tool kit of options made available by our culture and society. We do make choices, but we do not determine the options among which we choose" (Appiah, 1994: 161) . With this in mind, Nesta has a choice to make about attending TS support groups and risk being triggered by race-based coprolalia or continuing to stay physically isolated from the Tourettic community in order to feel safe based on non-TS elements of his identity. It is important to here highlight that this is a valid decision made by Nesta, and it is intersectional considerations such as in this example that urge us to value and support the decisions made by members of our (Tourettic)

community, withholding judgement and assumption about whether or not something is a 'good' decision.

With the aforementioned examples in mind it's important to consider how whilst intersecting elements of identity such as ethnicity, gender and sexuality can have an impact over which spaces people feel comfortable accessing or navigating, there is strategizing that takes place to weigh up the risks of opening yourself up to the potential negative chance encounters found within a given space, whether that is in the transphobic slurs mentioned by River, Nesta's avoidance of in-person Tourette Syndrome-specific support groups (which will be discussed at greater length in Chapter 5) out of concerns over exposing himself to racial slurs as a result of coprolalia; or even in Bella's previously explored attempt to remove herself from a space shared with a woman who was wearing a hijab when shopping. The potential for negative experiences occurring as a part of any given chance encounter is something that is considered in the Tourettic strategizing that is inherent to the embodied experiences of public space for those with Tourette Syndrome. This strategizing is incredibly important to consider. Tourettic people are considering the interactions between people that happen in differing ways in different spaces that have different social norms and general expectations in an attempt to have some control over the directions of the chance encounters they may have. When is the best time to tic to go unheard? When is it *worth* the energy of redirecting a tic to pass as non-tourettic? All of these questions concern finding and navigating the pockets of opportunity for chance encounters – whether positive, negative, or somewhere in-between – in ways in which the strategizing that is distinct to the Tourettic experiences of public space is required in order to mitigate any risk. Again, this distinct strategizing is vital to consider in the inquiry into the embodied, Tourettic experiences being had within public spaces.

#### **4.4 Lingering deposits of dialogue and their implications**

These impulsive experiences, managements, and negotiations of chance encounters all have impact that lingers, ~~so to speak~~. Whether in the vocal tic, another's response to said tic, or underwriting feelings of impulsive uncomfortability in a given moment, the Tourettic body leaves particular deposits on the dialogues that occur within any given encounter with/in public spaces that underwrite dialogues and chance encounters with impulsivity. Adrian's feelings of significant uncomfortability in bar

mitzvahs that he attended as a child still remain, the deposit still significant enough to influence the kinds of spaces that he avoids. For Bella, discussing how she *knew* she was going to tic “ISIS” at a woman wearing a hijab was aware of previous dialogic deposits in the form of coprolalic tics and so it remained, or lingered, and influenced the ways in which she navigated the shop in question. Lizzie expressed anxiety about being in public places without a social buffer due to past experiences; Leonard even implied the subconscious Tourettic awareness of noises to come in the form of a door making noises as it closes providing a space to tic or to release the impulse within, whether intentional or not.

It is precisely these examples that emphasise the fundamental importance of considering impulse and chance encounter within inquiry into the Tourettic embodied experiences of/in public spaces. Chance encounters are influenced by affective deposits, and these deposits are why the dialogues occurring within them linger and continue to impact future encounters. These deposits occur in these pockets of opportunity, facilitated by a sense-of-anonymity, and catalysed to some extent through premonitory urge for many. What we remember, however, of dialogues and chance encounters, are simply caricatures of them; the caricatures of dialogues are what linger. We think back to experiences and chance encounters that we’ve had and remember the dramatics. We remember the very worst and the very best of experience; only the most disruptive tics will be remembered in the most disruptive of instances; the most emotionally jarring elements of chance encounter(s) are what stick with us, whether positive or negative.

With this in mind, it is important to remember that all dialogue is relayed; if we consider dialogues (both verbal and non-verbal) as key elements of the chance encounter, we must remember that none of this occurs in a way that is temporally fixed. Again, the fact that Adrian’s experiences of a childhood bar mitzvah influences him still, many years later, is one example of a plethora of evidence of for this. One chance encounter will influence the next, and the next, and the next. They layer and layer and continue to have impact. With impulse playing such a significant role in the ways that chance encounters are navigated for tourettics, it’s important to acknowledge that these timely impulsivities will have an impact that is not temporally bound. Kacy might tic, look over her shoulder as if she is searching for the source of the sound, and her fellow shoppers may be confused about what the sound was. They might then remember this

*strange disturbance* and discuss it in other conversations they have later on. Or perhaps even somebody saw Kacy tic and pretend it wasn't her. Perhaps this faux pas will be remembered by somebody, and this memory lingers on into future conversations, dialogues, etc. Let's say that, for example, Bella *did* tic "ISIS" at the woman who was wearing a hijab in the shop. Perhaps this would have resulted in Bella disclosing her diagnosis as a technique for managing the encounter. This jarring experience may be the only thing this woman remembers, as the caricature of this chance encounter that lingers in her mind, and perhaps it will influence how she interacts with other tourettic people in the future. Would this experience result in her feeling an inevitable discomfort when she meets somebody with Tourette Syndrome? Would it allow her to feel *more* comfortable in knowing, to some extent, what to expect from somebody with Tourette Syndrome? Whilst the ways in which the lingering deposits of encounter influence future experiences, both for tourettic and non-tourettic people alike are undefined, it is clear that these experiences are key precisely because impulse is so significantly prominent in the Tourettic embodied experience of public space.

The implications of the dialogues occurring between impulsive (Tourettic) bodies and chance encounters within public spaces are, again, undefined but categorically significant in thinking about the embodied experiences of public spaces for Tourettic people. Impulse is something that results in the distinctive nature of the Tourettic embodied experience of public space. Impulse is key to the ways in which tourettics within the pool of participants for this research understood their own bodies and understood the ways in which they navigated through public spaces. Memories, experiences, and encounters of, with and within public spaces were significantly influenced by impulse, to an extent that is distinctive from that of the non-disabled person/body. This impulse is evidently significant in physical public spaces, but this then raises further questions as we continue to exist in an ever-digitising. I acknowledge in this chapter the influence that impulse has on dialogues occurring within public spaces (in the physical realm); we say that dialogues linger and are ever-relaying and that they continue to impact future encounters to come. If this is the case, then it's important to ensure we consider other dialogues that occur, and how impulse influences those also. Not only can impulse influence dialogues between bodies, both human and non-human,

but also the ways in which dialogues occur between the physical and digital realms (of which the next chapter shall discuss).

#### **4.5 Concluding points**

The experiences that were shared with me throughout the data collection were extremely varied – after all, Tourette Syndrome is an incredibly varied condition, and no one person has the same experience of it, regarding its symptomology alone. However, using the framework of chance encounters and impulse offers us some points for consideration. Chance encounters are key in considering how Tourettic impulse influences embodied experiences in/of public space; impulse changes everything surrounding chance encounters. Experiencing first-hand Tourettic impulse results in creativity that is inherent to the Tourettic bodymind. There is creative strategizing that takes place prior to a forthcoming encounter; there are creative improvised responses that occur during an encounter; and there are creative reflections afterwards that occur and look then to influence the creative strategizing work that takes place. It acts like a cycle that is ongoing, and this is greatly influenced by impulse.

This cycle that is distinct in the case of Tourettic embodied experiences of public space is evident in all aforementioned accounts within this chapter. However, returning to the example of Kacy now, she plans strategies when using public spaces, simply through the knowledge that she feels more comfortable being in public spaces alone or with people who do not know about her diagnosis of Tourette Syndrome. This is so that it is less likely that people will disclose on her behalf – this is something she knows will grant her autonomy and some level of control in any given chance encounter. It is this which facilitates her then improvised response of ‘looking behind’ as if to search for the source of the disruptive sound (vocal tic). Through reflecting after the said chance encounter, she knows this somewhat softens the blow, regarding how this response makes her feel actively *not* stared-at – this reflection does and will continue to linger as she continues to use public spaces.

The distinctiveness of Tourettic embodied experience then is precisely in this inherent requirement or need to creatively interact with the chance encounters that populate public spaces. Whilst the precise ways in which impulse influences embodied experiences in terms of which emotions are felt; which spaces are enjoyed or detested; and so on, are incredibly varied on the individual scale, the constant is simply in the

'required' strategizing, responding, and reflecting that Tourettic people 'do' as a result of the unique experience of impulse. Whilst significantly influenced through the impulsive body, it is important to acknowledge that public space and its design is still very much influential here. The requirements for this creative strategizing are in part created through the ways that public space is not necessarily *open to difference*, whether through aforementioned concerns surrounding getting about whilst using mobility aids, or through the ways in which it normalises practices of queuing or other mobilities, and even ways of *being* and *doing* that demonize ticcing that render these spaces inaccessible for tourettic people. All of the aforementioned adds to the additional labour *required* by tourettic people in the management and risk-assessing of chance encounters that occur within public spaces. The chance encounter is underwritten in distinct ways for distinctively impulsive people (read: tourettic), and so considering the chance encounter is key in the way that we conceptualise the tourettic embodied experiences of public spaces, and the ways in which public spaces can work to facilitate sense of belonging or/and exclusion.

## Chapter 5. Tourette Syndrome, Public Space & the Importance of Community

### 5.1 Introducing community as a public space

There is a centrality to community and its role in managing public spaces. Belonging within the community, broadly speaking and on the societal level, is of key importance to people. The role of community in this sense is also linked in with the associated chance encounters that Tourettic people have, as has been explored in the previous chapter. With the creative strategizing that takes place in and around the use or navigation of public spaces, it is important to consider community as an important factor when inquiring into disability, wellbeing, and embodied experience(s) of disability (Dunn & Burcaw, 2013; Verdonschot *et al.*, 2009). Imaginations of community are typically quite broad, as this statement on the website of Liveability<sup>21</sup> suggests: “A community that will still push you to be your best and encourage success is the most important to anyone, whether that’s friends and family or support workers and physiotherapists. It’s more important for someone with a disability as they won’t treat you any differently. It’s good to have people that have got your back” (Long, 2016). However, this chapter hopes to expand imaginations surrounding *community* and push towards a focus on *a*-Tourettic people aside from non-Tourettic stakeholders such as parents, siblings and partners. In doing so it offers nuanced consideration as to the relevance of finding a community, or *kin* (Wade, 2019) of others who share similar lived experiences to you. In the context of hostile and unwelcoming social dynamics, people whose identities are positioned as different can seek to create their own spaces of belonging and *communitycommunity*. This chapter examines the importance of community for Tourettic people and how that is produced/practiced.

The topic of community has been greatly discussed across disciplines, with frequent consideration of how to define it (Milner & Kelly, 2009; Simpican *et al.*, 2015). The point that stands in this chapter however, is that “[p]laces are not necessarily communities” (Bradshaw, 2008: 5). With this in mind, public places can be a plane upon which community breaking or making can occur. Whilst acknowledging literature

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<sup>21</sup> Liveability is a disability charity who aim to connect and facilitate community amongst disabled people and aim to raise awareness of a range of disabilities

highlighting the work that goes into community building (Edwards, 2022; Wade, 2019), by considering a *community* not as an imagined public or a place as a whole but perhaps as a particular imagined *kin* of sorts that is facilitated partly by chance encounters that occur in physical public spaces, this chapter considers the distinctive importance of the consideration of community within inquiry into the embodied experiences of public space had by Tourettic people. It is well-documented in published literature that there is limited support available for those who receive a diagnosis of Tourette Syndrome (Debes *et al.*, 2008; Perkins *et al.*, 2020) and the effects of this are feelings of isolation, loneliness (Malli *et al.*, 2019) and repeat stigmatisation (Bervoets *et al.*, 2022; Malli *et al.*, 2016) as Tourettic people feel *othered* through various processes that occur in public spaces, as the previous chapter discussed.

The reasons for the importance of the inquiry into Tourettic embodied experience of public space come from the distinct experiences of loneliness had by Tourettic people, both outlined in previous literature and also within the data collected for this project. Loneliness is largely considered an area of increasing concern and has been explored by many scholars in recent years, with arguments in circulation surrounding the increase in the experience of loneliness particularly in places where access to social media and online space is higher (Snell, 2017). Amongst arguments of increasing levels of reported loneliness in the general population in line with increased time spent online (Alberti, 2019) we must acknowledge that due to existing experiences of isolation experienced through aforementioned *othering* practices in public space, this ever-increasing loneliness disproportionately effects the Tourettic community.

With this in mind, this chapter's interest is centred around community groups, also referred to as support groups, for those with Tourette Syndrome. Community, support groups, and public space as terms overlap here, but are distinct from one another. For the sake of clarity, it is useful here to elaborate on these terms by defining their scope within this chapter:

- *Community*: feelings of community and/or kinship within a group, whether amongst a wider imaginary public of Tourette Syndrome or of disabled people more generally speaking

- *Support group*: organised groups, whether in person or online, that are designed to *house* those looking for support. These could be self-organised, or organised by charities with funding
- *Public space*: spaces, physical or digital, that facilitate the chance encounters aforementioned within this thesis.

To elaborate on the way in which this research approaches or understands *community* then, is as a *catch all* of the above. Community has many scales, and can be found in the more abstract feelings of community and belonging to an imagined community of disabled people, or perhaps can be experienced in the context of support groups, whether online or physically facilitated. Community might be found in public spaces or private spaces, and in the context of this research is understood as a system which provides a sense of belonging of sorts, regardless of scale or context.

Considering the support group as a form of public space then, given that within these groups there is potential for chance encounters and a supposed requirement for the implementation of creative strategizing work, the case of the support group offers significant insights into some of the processes that hold influence over the Tourette embodied experiences of public spaces. This chapter will consider the sense of community [sometimes] fostered in these support groups and consider processes of [un]belonging at play within them. More broadly speaking, many support groups are facilitated in and around well-considered public spaces such as cafés, for example. For some these neutral spaces allow people to feel a sense of belonging and acceptance rather than the associated feelings of being cared for or of *needing* support present at specific spaces designed for the facilitation of support (Kurtz, 1971). The same value and relevance here also goes for that of the Tourette Syndrome support group. Support groups are vital for many, and there are some distinct processes happening in the case of Tourette Syndrome support groups that have impact on the ways in which public spaces are used and experienced both physically and digitally for those seeking support. A key element of digital support seeking is social media. Conceptualising social media sites as public spaces also, within which chance encounters can be facilitated, this chapter echoes Alberti's (2019: 131) work that claims the unhelpful nature of "lament[ing] the rise of

social media as an inevitable cause or repository of social ills” inclusive of Tourette Syndrome.

Throughout the project there were multiple examples raised that considered elements of community. Whether in Tabitha’s accounts of participating in an international Tourette Syndrome exchange, or in River’s coprolalia that manifested as homophobic and transphobic slurs when trying to attend an LGBTQ+ Pride event as a trans man himself. These accounts vary significantly from person to person, and this chapter will consider particularly the processes that happen in and around communities as public spaces in which chance encounters are facilitated and strategic management is required. Further to this, an intersectional lens will be applied in thinking about how *membership* or association with multiple communities (Bradshaw, 2008) changes the processes and contexts of chance encounters. Through doing this, insights are drawn into the reasons ~~for which~~ why the digital realm is so important to consider when inquiring into the embodied experiences of public spaces had by Tourettic people, and what the implications of doing so are for recent Tourette Syndrome discourse more generally.

## **5.2 The need for spaces of Tourettic sense-of-community, support groups, and support**

Chapter 4 delved into some of the many alienating experiences of public space for adults with Tourette Syndrome. This alienation can lead to feelings of loneliness and isolation, and it is for this reason that community is particularly valuable for tourettic people. For academics and healthcare practitioners, loneliness is considered an increasingly concerning experience (Buecker *et al.*, 2021). People with a diagnosis of Tourette Syndrome are disproportionately affected by this increasing loneliness, and has been referred to by many as a notoriously isolating disability, whether through increased levels of *othering* occurring through peer victimization for those experiencing tics, or through stigma surrounding the idea of dating someone with tics out of want for a *normal* partner, as just two examples (Debes *et al.*, 2010; Malli *et al.*, 2019; Malli & Forrester-Jones, 2017; Storch *et al.*, 2007). With loneliness on the whole being on the rise, it is important to acknowledge the significance of loneliness and isolation as a part of the Tourettic experience, especially given it’s repeated mentioning within this project’s data.

Significantly further work needs to be done regarding this. Generally, the majority of literature surrounding Tourettic loneliness and isolation focuses on young people

(children and adolescents) be it in teens wanting *normal* (read: non-tourettic) romantic partners (Malli & Forrester-Jones, 2017) or more generally regarding writing surrounding stigma and its influence (Leckman *et al.*, 2006; Malli *et al.*, 2016; Rindner, 2007). However, there is a greater need to consider Tourettic adults and their experience of loneliness. This has been considered in regards to stigma (Malli & Forrester-Jones, 2021) but not specifically regarding loneliness. Simply put, these Tourettic young people become Tourettic adults (Jones & Phoenix-Kane, Forthcoming), and with the transition into adulthood loneliness can linger. Resultantly, loneliness and isolation underwrite the context for this chapter.

With this in mind, there were accounts from the collected data ~~within this project~~ referring to this same isolation and loneliness, seeming to span across various stages of the Tourettic life-course. For example, River – a young trans man with comorbid diagnoses – referred to the isolation he felt as somebody with Tourette Syndrome who hasn't yet received a diagnosis:

*I didn't have a diagnosis [of Tourette Syndrome at that point] and I wasn't really bothered about having a diagnosis really because of my past experiences of getting diagnoses and yeah, it doesn't always help and often it can cause more discrimination; more misunderstanding and more maltreatment by professionals, so I didn't really want another reason to be... yeah, completely isolated and discriminated against*

- River, Interview 1

It is evident to see here the impacts of loneliness and isolation that were somewhat expected to follow diagnosis, or to come with the process of seeking diagnosis, of Tourette Syndrome. Prior to River's diagnosis journey, he was aware of the stigma and isolation that seems to be associated with Tourette Syndrome. However, with accounts of fake-claiming and accusations of faking tics rife within certain groups within the Tourettic community, this lack of diagnosis is something that further adds to experiences of isolation, and therefore of loneliness too in the way that people can be pushed out of community spaces without proof of disability. It is such experiences of loneliness that are key to consider when thinking about the importance of connection and the finding of a sense-of-community within support group contexts. Tabitha neatly summarises this in stating that "there's very few conditions that can be as sort of frustrating or sort of as isolating as Tourette's, and so for me it's quite important to connect with other people with the

condition, just to feel a bit less alone” (Tabitha, Interview 1). There is evident *power* in the simple feeling of being ‘a bit less alone’.

In addition to this, Ricki speaks of the importance of finding connection with other Tourettics:

*I think it's quite important for me that when I see someone that I know who is ticcig to be like “I also have Tourette's, this is a shared experience” because I know how lonely it is having a diagnosis where no one else talks about it in the same way. Part of that for me is that in high school one of my really good friends, their name's [redacted], they had really, really loud coprolalia-like tics, and they sat me down in lower sixth form and was like “I have tourette's. You have tourette's. Let's talk about this” and it was amazing to see someone that... yeah, they spoke about it really amazingly and just seeing somebody else with Tourette's was really important to my late-teen development of starting to be okay with it and with being disabled.*

- Ricki, Interview 1

Ricki here refers to meeting others diagnosed with Tourette Syndrome as a key part of becoming *okay* with their disabled identity<sup>22</sup>; something which is fundamental in ensuring the wellbeing of disabled people more generally (Higgins *et al.*, 2002). Having opportunity to meet others with a diagnosis of Tourette Syndrome was key in combatting the loneliness Ricki felt from “having a diagnosis where no one else talks about it”. Similarly, returning to Tabitha once more, for her finding community was also instrumental for her own wellbeing.

Whilst the effects of lingering loneliness may differ on an individual scale, it seems that for the large majority within the context of this research's participants, this experience of loneliness was the reason for seeking out support groups and Tourette Syndrome communities. This is directly connected to the experiences that are had in and around physical public spaces. Prior to receiving diagnosis or finding support group to access, many Tourettic people have never met anybody else with TS (at least knowingly). To draw on personal experience here, as previously outlined, in my dual role of researcher and expert-by-experience this has [also](#) been the case for me. I never knowingly met anybody with Tourette Syndrome until I decided to conduct research as a part of my

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<sup>22</sup> Here, Ricki uses ‘disabled’ to refer to a wider part of their identity, as ‘Tourettic’ is not language they were familiar with. Throughout discussions they used ‘disabled’ rather than ‘Tourettic’, as a more specific descriptor, as they felt more comfortable with this way of describing themselves. As such, I have mirrored this use of language here to respect the preferences of the participant.

master's level thesis, which concerned Tourette Syndrome. After this research ended, I did not knowingly meet another person with TS until engaging in this PhD project. This was despite having received a diagnosis as a young teenager. Even as a Tourettic person who was engaged with TS research, this loneliness lingered as my previous engagements did not necessarily result in the ability to access support groups or even a sense of community. In the same way that Kacy, a healthcare professional based in the South of England, didn't learn about TS until conducting research and studying for a degree, I hadn't learnt of the support groups and networks (as limited as they are/were) that did exist at the time. My tourettic experience was lonely, and that very much felt inevitable to me.

What is key to recognise here is that these experiences of loneliness linger and influence future chance encounters in a multitude of ways. For River, this previous experience of loneliness and discrimination that resulted from previous diagnoses resulted in actively not seeking support that may have required medical diagnosis of Tourette Syndrome to access. This is despite his knowing that he exhibited all of the relevant symptoms for a clinical diagnosis. This impact lingered and resulted in River not feeling able to reach out for support in some instances. For Ricki, this previous experience of loneliness underwrites their reasoning for always disclosing their own diagnosis of Tourette Syndrome when they see somebody else tic in public to make them feel less alone; Ricki didn't want a fellow ticcer to feel as isolated as they had done prior to meeting others with Tourette Syndrome. Tabitha's experience of isolation resulted from the frustration that others can't quite comprehend her experience. This, in turn, led to her involvement as an advocate and now staff member roles at a large Tourette Syndrome awareness charity on the side of her full-time employment. All of these lingering deposits affect future chance encounters through the creative strategizing and the attempt to support others in their navigation of potentially stressful chance encounters arising from tics. River's method of managing potential future chance encounters surrounding diagnosis was to simply not seek out a Tourette Syndrome diagnosis, for example. The experiences of loneliness linger and are very much folded into the ways that these chance encounters are navigated and their management strategized in the case of Tourette Syndrome.

It is important to acknowledge here that support groups, as spaces that foster the development of a sense-of-community (or belonging), are spaces within which chance encounters can occur, hence the reference to them as a form of public space. The encounters happening within these support groups are equally ‘managed’ and attempted to be controlled by people, much like encounters in places such as shopping malls, elevators, and so on (see Chapter 4). Participants seemed to discuss the chance encounters in support group spaces in a positive light. In particular, Tabitha, as aforementioned, discussed her expectations of encounters happening in these support groups to increase this sense of belonging through making people feel “less alone” (Tabitha, Interview 1). It is important here to highlight that this sense of belonging does not come from simply knowing other Tourettic people. Edward is a man in his 50s based in the US who by chance attends a church in which one of the pastors has received a diagnosis of Tourette Syndrome. Within the interview, Edward expressed that they have never had a conversation about their experiences of Tourette Syndrome, and descriptions of their relationship appeared to be more professional, or distanced, than personal and fostering a sense of belonging. Similarly, Simon referred to meeting somebody with Tourette Syndrome but also spoke of how he didn’t really feel a close connection to other Tourettic people. The encounter he brought up was one that occurred in a fleeting, more professional context as it was somebody working at a bank to advise him on his mortgage.

The encounters here had by Edward and Simon were not of the community-building kind. By this, I mean to say that they were moments in which any form of loneliness that may have been experienced at the time by each participant would not have been mitigated through these encounters. The professional dynamic that is subject to strong power dynamics, such as pastor-congregant or banker-customer, limit the building of community and belonging in a way that is not necessarily the case when it comes to the slow building of relationships that might occur through dedicated support group space attendance, for example. In particular, one participant’s accounts of belonging and community stood out to me. Madge is a 65 year-old woman from the South of England, who received a diagnosis of Tourette Syndrome after being given a course of ciprofloxacin<sup>23</sup> whilst in a hospital stay, which resulted in an onset of tics. She stated, “I’ve

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<sup>23</sup> A fluoroquinolone antibiotic used in the UK to treat a number of bacterial infections, including but not limited to pneumonia, gonorrhoea, and typhoid fever.

never met anybody with it. I've never met another sufferer, never met anybody else” (Madge, Advisory Focus Group), and in an interview the following dialogue occurred:

*RESEARCHER: So... you said obviously you don't really want, you know, doctors to be involved anymore. I'm just curious – in terms of [...] support... do you have any kind of support network of anybody with Tourette's?*

*MADGE: Who? Where do I go? Who wants to know? No one is interested. And no one can do anything, I mean no one... most people probably wouldn't believe me, or would they? I don't know. I showed you the link I don't know what or how much you believe of that. It's so rare, it's very rare. Although interestingly enough I've met a lady who thinks she's got a friend who's got similar symptoms.*

- Madge, Interview 1

This conversation struck me, especially in Madge's question of “Who wants to know?”. The idea that nobody would believe her story was interesting to me. Not only had she never met anybody else with Tourette Syndrome, but she could not comprehend the idea of a support network where she would be valued and accepted, or where her story would be acknowledged. This lack of access to a support group, or sense of community/belonging, led Madge to thinking that nobody would care about her experience of Tourette Syndrome, with mentioning of knowing that people would not believe her story even if she did have a chance to share it. This lack of community and distrust of these spaces is significant in adding to the loneliness and isolation throughout the project's participants; isolation and loneliness were key to the ways that participants narrated their experiences.

However, for those who had been successful in finding the support groups (seemingly a limited number based on data) or who had found a sense of belonging through other means discussed this sense of community found in support groups as important to their wellbeing as Tourette people. Having access to a support group as a form of public that fosters this sense of belonging is incredibly important for reasons outlined by Yebby, a queer northerner in her early 20's:

*I think it's like you're a walking billboard for Tourette's [...] usually [with] the little tics, [people] end up being just a bit like “ooh that was a funny noise” kind of look, and they shoot a look where they're trying to work you out, and then I think with the bigger ones, even though people see them and think “Oh that's Tourette's, definitely”, they seem to be more like a taking offence sort of thing, and there's been times when people have*

brought things I've said to my attention and I've said "Honestly, it just sounds like noise to me, it doesn't sound like I'm saying words anymore". It's just noises. Um... but yeah... then I think just kind of any negative attention really.

- Yebby, Interview 1

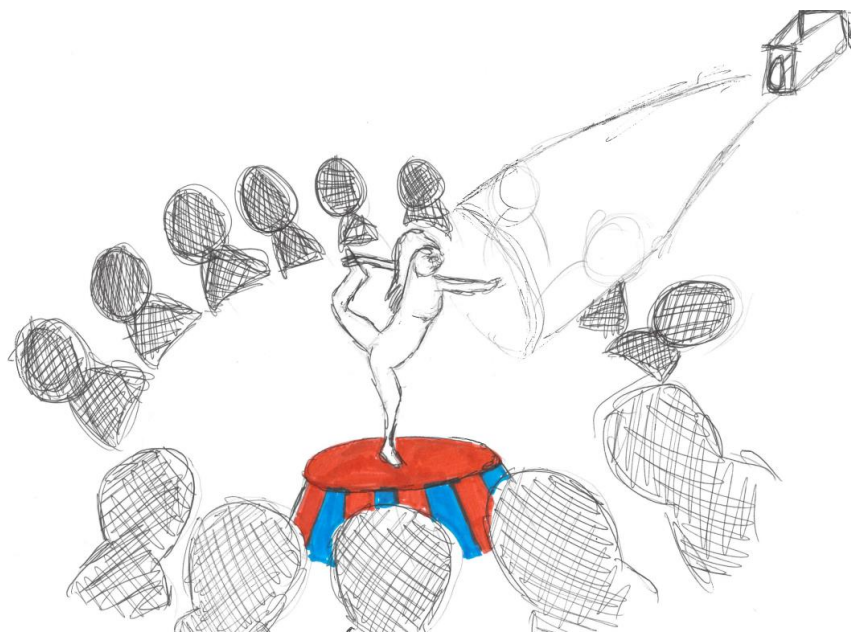


Figure 2: A piece by Yebby created in the zine workshop, exploring how she feels singled out and the center of attention when in public space.

In referring to being out in public as being like a “walking billboard for Tourette’s”, Yebby is outlining the negative attention she receives as a result of her tics. In the zine workshop, she followed up on this idea by creating a piece of artwork for the zine (Figure 2) that highlighted the isolating impact of these stares and glares (cf. Garland-Thomson, 2005, 2006) that occur as a result of being this *walking billboard*: “I’ve always been one to enjoy going unnoticed. That’s always been me like just being unseen and not heard, but now I’ve got no option but to be seen and heard, and that’s exactly how it... what I drew is just how [isolating] it felt” (Yebby, Interview 2). It was in the Touretic community focused support group space where Yebby found greater comfort. The othering practices of staring and glaring added to her isolation and loneliness, but after joining a support group she found that it was a more accepting environment where she didn’t feel as singled out as

she did in other spaces; there was a greater sense of belonging being experienced (Yebby, Interview 1).

It is evident that there is need for Tourettic support groups that provide a sense of community and belonging in order to combat disproportionately increasing loneliness in the case of Tourette Syndrome. There is an inherent importance to them, and regarding this it is vital to consider the encounters that (can) happen within them that work to combat this loneliness and isolation. For Yebby, she had never met anybody with a diagnosis of Tourette Syndrome prior to attending a support group with this research's collaborators, TIC-Hull. She shared with me throughout the process of conducting this research about how incredibly important this support group has been for her, and how she often felt like the centre of attention – something she didn't want – until engaging in the community building processes of participating in the support group. However, the process through which Yebby went in order to get to the point of attending this support group physically is of particular importance...

### **5.3 The digital shift in support and sense-of-community**

There is a significant shift to the digital occurring when it comes to support group facilitation. Social media sites, WhatsApp groups, and so on are becoming increasingly significant in accessing support, particularly given the limited availability within the UK of TS support. For Yebby, digital space was a fundamental part of allowing her the comfortability to eventually engage in the in-person support group space hosted by TIC-Hull. Joining a Facebook group with members of the community was fundamental in Yebby being 'convinced' to attend in person, to use her own words (Yebby, Interview 2). The digital space, in this instance, acted as a stepping stone to attending the in-person group, which in turn then allowed Yebby to become more comfortable and engage in the community building practices occurring at the in-person support group.

Amongst the research participants as a whole though, it was clear to see that online spaces are not solely stepping stones to enabling access to physical, or in-person, support groups. As previously mentioned, many participants expressed that there were no in-person services available to them at all. In these instances, lacking sense-of-community and feelings of isolation and loneliness resulted in people seeking out this sense-of-community online. The absence of in-person support for many is what is driving

their search for belonging and a sense-of-community online. There are multiple ways in which digital spaces were used to facilitate this that were raised throughout the data.

Aside from the common experience of having never previously met anybody with Tourette Syndrome, a shift to online groups has been further encouraged due to the pre-existing physical Tourette Syndrome support spaces and services either not matching expectations or the requirements of Tourettic support seekers themselves. For Leesh, this happened in the instance of a support group for adults not actually offering support to Tourettic adults themselves:

*...the adult group was parents and it was parents that wanted reassurance that their kids were not going to have terrible lives, and so it was a very awkward position for me to be in because I went in hoping to get support for myself, and basically they were looking at me as the support pariah*

- Leesh, Interview 1

Here Leesh refers to a support group that advertises as being 'for adults with Tourette Syndrome', to which she was signposted by the healthcare professional who diagnosed her. What is particularly interesting here is Leesh's use of the word *pariah* when describing her role as support-giver in the context of this support group. By nature of having a diagnosis of Tourette Syndrome, she was thrown into the role of giving reassurance to parents of children with Tourette Syndrome to tell them that their lives would not be inevitably dreadful. In doing so, Leesh clearly felt *othered* within the context of this group, despite it being advertised as primarily *for* Tourettic people themselves. Loneliness is not only found in the lack of community, but can also be further facilitated through the *othering* of placing the 'pariah' narrative upon them, in a similar way to how Ricki referred to not feeling that he had a *true* supportive community because they were so involved in supporting others, and that is what they became known for (Ricki, Interview 1). Having Tourette Syndrome in this instance resulted in being *othered* even within the TS support group run by the charity in question. This was raised elsewhere too. When asked about the creation of TIC-Hull, charity CEO Kim Mitchell stated:

*Upon receiving the diagnosis of Tourette Syndrome for my child, I was struck by the lack of support accessible to both my child and our family. Working within a healthcare environment accustomed me to receiving comprehensive training across various areas to enhance staff understanding of the conditions encountered daily. However, it was concerning to observe that medical professionals and educators exhibited minimal knowledge of a condition impacting approximately 1 in 100 school children. This*

*realisation grew more disconcerting as our circumstances worsened and I encountered adults facing similar challenges. Establishing the charity aimed to unite a community, offering peer support, a secure refuge, and eventually educating individuals surrounding our children and adults, providing them with the necessary support throughout their lives. Every individual deserves a comparable quality of life, and through our organization we strive to realise this aspiration.*

- Kim Mitchell, TIC-Hull, 2024

Evidently, the cornerstone of the charity was providing support for children. Whilst eventually moving into considering adults, the starting point was that children were not receiving the care and support that they needed in educational contexts. It is experiences like these, combined with general processes of othering that occur elsewhere and the foundational aspirations of organizations such as these, that can oftentimes cause hesitation and concern over various support groups, being one of the reasons that these online groups are important. Accessing the online equivalent of an in-person support group allows a more hesitant toe-dipping approach to exploring the place in question.

This process of Tourettic people being othered within Tourette Syndrome spaces extends beyond the support group setting, and into wider Tourette Syndrome events and services also. In an interview with River, he shared with me his experience of Tourette Syndrome residential trips organised by a Tourette Syndrome awareness charity:

*There's been some situations where, at events, like at the Tourette's residential camps, someone was kicked out because they had violent tics, and that is \*surely\* part of having Tourette's. It made no sense, and it felt like the whole of the charity was just kind of accepting and creating a space for palatable people with Tourette's, rather than people with more severe cases or people who are taller and appear more menacing and aggressive but they're not; they're just disabled.*

- River, Interview 1

This interview clearly highlights the issue with many existing groups and services that do exist, particularly in reference to charities “creating a space for palatable people with Tourette’s”. This is important to consider, along with other disappointing experiences of in-person support groups in contextualising the reasons for this digital shift in support. People are looking online for support as it offers the opportunity of testing or being able

to gauge the kinds of ~~encounters~~ encounters that one might have in said support group prior to physically attending (that is only *if* they offer in person support, which is not common); ~~so to speak~~. In River's account, this is particularly in relation to *who* belongs or is allowed to feel this sense-of-community in the given space dependant on how *palatable* their symptoms are. What appears to be palatable in this instance is suggested to be those who's tics are least disruptive, perhaps with a particular exclusion of those with coprophobia present within their symptomologies, but also those who may be tall, or occupy more space physically as per Pete's reflections (Pete, Interview 1).

Leesh and River offer just two accounts here of the shortcomings of physical support groups or community activities that they have experienced, and these are key reasons for which Tourettic people involved in this research have sought out community in online spaces. Othering practices have been occurring in Tourettic spaces (most often the ones that are facilitated by non-tourettic people). These othering practices are key in the argument that existing support services are not only unsuitable in terms of availability, but also in terms of their adequacy. These experiences also point to the fact that bringing people together in a physical space based on shared experience of a disability does not necessarily result in the finding of a sense-of-community. This is a concern shared with other marginalised groups also, and that has been explored within the study of sexuality and queer politics. Notions of the good homosexual and the dangerous queer (Smith, 1994, 1997) were key in the queer politics of the 1980s along with ideas of a *new* homophobia. Key here is the separation of queer people into 'dangerous queer' and 'good homosexual' in that the simple belonging to the same marginalised identity group does not necessarily mean that all LGBTQ+ people are welcomed in this regard. Society could accept the 'good homosexual', but the 'dangerous queer' did not fit society's imaginary. There have also been similar debates present in disability politics between support groups that are more medicalised in their understanding of disability and those with more activist and social model approaches to disability. Morris (1997) writes how 'care' ~~and~~ 'empowerment' cannot occur together, and are mutually exclusive, problematising the notion of 'caring'. It is the notion of 'caring' that many of these support groups are built on, and so it is also key to acknowledge that 'caring' does not equal 'community-building' when it comes to these spaces.

With this in mind, it could be said that the removing of certain symptomologies from the aforementioned TS residential events in an attempt to ‘care’ for other attendees is actually a violent act that removes any and all opportunity for the empowerment of Tourettic people. In the same way, parents asking for ‘careful’ encouraging words to be shared to remove worry about the assumed impending dreadful lives of their children is very much a disempowering process for Tourettic people. In starting from the perspective of ‘care’ the problem arises that medicine and its symptomological focus “enters the domain of identity politics” (Hughes, 2009: 686) and influences who can and cannot access support and sense-of-community, all whilst under the disguise of so-called ‘caring practices’ being enacted. Questions of “*who needs more care?*” and “*who is more tourettic?*” may arise. In talking about her history and experience with tics, Bella mentioned to me how she used to have “little quirks” that people might refer to, but that “now [it might be described as] big tourette’s” (Bella, Interview 1). These assumptions and identities seem oftentimes assigned by non-tourettic stakeholders, as a way to make sense of Tourette Syndrome and tics. Whilst identity politics could be said to be an inherent part of my call for greater recognition of tourettic experiences, there is something more needed about the non-tourettic assigning of ‘extent of’ identities, such as trying to describe somebody as having ‘big’ or ‘little’ Tourette Syndrome. Practices presented as care, or as caring, are part of the processes of exclusion that can occur in these spaces. Notions of *caring* might further infantilise Tourettic adults in that they might be assumed to be unable to exist independently. Again, this also extends to Leesh’s experience of being othered through the expectations of sharing *carefully* thought-out responses to non-tourettic stakeholders who were worried about the impending dreadful remainder of their tourettic loved one’s life. In the case of Tourette Syndrome, this belonging and sense-of-community can come from a solidarity-focused approach to support, services and activities (as will be discussed in Chapter 6), and is limited by othering processes sparked by both Tourettic and non-tourettic people alike. There are hierarchies of power at play here, whether in Leesh ending up with a responsibility of care for non-tourettics, or River in his experience of more palatable symptomologies being prioritised in their support. A shift to seeking out support and community online occurs as a result.

A significant number of participants shared with me how they sought out community by looking for pre-existing online groups on platforms such as Facebook. There seemed

to be hopes of a less damaging space of support and service provision within these online platforms. However, these were often under-resourced, and as a result their stability was poor. Joey, a young Australian man who had never met anybody with Tourette Syndrome at the time of our first interview, shared:

*I... I don't think so [...] before I joined [group name redacted for anonymity] I was in a group, uh... Tourette's and Autism Awareness Group or something... yeah... um, unfortunately the funding got withdrawn from that and, God bless her, the woman that actually ran the group died and uh yeah, so did the group itself, but... um... I think from that I joined [other groups]*

- Joey, Interview 1

Joey shared with me how once one group closed due to lack of funding and leadership, he ended up searching for another online support group to suit his needs. However, this was mainly due to his previous positive experiences of online groups – he shared that the only reason he joined the previous group that closed down was due to a recommendation (and seemingly much convincing, given that some participants needed repeated encouragement to join these groups). This was a common experience that came up across the data. Whilst many took the first step in recognising their need for online support groups, others were encouraged by networks to seek out community in this way:

*So [name redacted] actually messaged me, and I cannot remember for the life of me how this happened. I do not remember, but... oh no! Maybe someone knew her and told her about me, and then she sent me a message, but yeah something happened and she sent me a message and I joined the group. I wasn't looking for one or anything, and I think I still, at that point, I didn't mind raising awareness for it, I was still embarrassed and ashamed of it enough to a point where I didn't want to be associated with any communities or people with Tourette's, because I still didn't want to think about it, you know?*

- Adrian, Interview 1

*My Mum recommended it to me from a work colleague of hers [who also has Tourette Syndrome... I enjoyed it because] a lot of other people you find share the same experiences as yourself. There's some good advice from other people.*

- Gee, Interview 1

Whilst some took their own initiative to seek out community groups, others were signposted through their extended networks, whether a colleague of a family member or a friend of a friend. However, what stood true throughout the data is the overwhelming focus on these online support groups when discussing support within the interviews. It was interesting here to see these spaces recommended by non-tourettic people, especially as it brings to light the assumed knowledge of Tourette Syndrome as a lonely and isolated disability. There is an obvious understanding of the importance of these groups, and in lieu of that understanding or knowledge, recommendations and signposting to these groups happen via the wider networks of Tourettic people. Uncertainty or lack of motivation to be involved with a support group was repeatedly brought up in the data, and it seemed that tourettic people oftentimes needed convincing to engage with support groups. This was the case as explored previously for Yebby, Joey, and Adrian amongst others. The ways that people who were not actively looking for groups to become involved with was through recommendations (and oftentimes convincing), but what is interesting here is the ways in which these experiences of the groups (once engaging with them) is significantly varied. The consistency seemed to be in the strong emotions associated with groups, whether positive or negative.

Talking particularly positively of a Facebook group run by a north-England based Tourette Syndrome charity, Bella shared the following:

*If you go into [the] Facebook page and you look and see someone is struggling [and has posted about it...] there's never a shortage of comments from so many people with their own experiences offering advice, help, their own techniques, or... you know, someone doesn't feel alone and like they're not the only one going through it. It's bloody incredible.*

- Bella, Interview 2

Here, we can see Bella sharing about her experiences of being involved in an online Tourette Syndrome support group that is hosted through Facebook. Evidently, there are strong emotional attachments for the Tourettic people involved in this project with online spaces of support and community that they have sought out and found a home in. One particularly important point that Bella raises here is the fact that if she were to ask a question in this group, she would be offered ~~advice~~ advice, ~~messages~~ messages, ~~message~~ message of

solidarity and shared experiences, and also signposting to relevant further support. The power of community-based knowledge production is clear here, and it is part of why these online groups in particular are so incredibly vital for the wellbeing of Tourette individuals. Examples of the importance of this were clear in the data, such as with Madge who said she had not accessed Tourette Syndrome support groups due to wondering “Who would want to know?”. She also referred to her symptoms in a way that is atypical to the language used in the case of Tourette Syndrome diagnostic criteria. In her interview, our conversation went as follows:

*MADGE: Because if something stressful occurs, I'll not... umm it's not necessarily the tics, but the noises it is. It's the noise I don't think I have any control over.*

*RESEARCHER: When you say 'noises' is that the noises from the tics?*

*MADGE: Well it's hard to say but Mmmm [high pitched squeak] WAAAH<sup>24</sup>*

*RESEARCHER: Ok*

*MADGE: It just comes out, I don't know it's gonna' do it and I just can't stop him [sic] and it's so embarrassing*

- Madge, Interview 1

As can be seen here, Madge, a woman with a clinical diagnosis of Tourette Syndrome, was unaware that her ‘noises’ were also tics, and are a symptom that is required for the clinical diagnosis of Tourette Syndrome according to both the DSM-V-TS<sup>25</sup> and the ICD-11<sup>26</sup>, which are taken to be the global gold standard(s) for diagnostic criteria/guidance. Madge was unaware that tics could be both motor and vocal, though this was a part of determining whether the diagnosis would be TS or another tic disorder/symptom from another condition. There were other instances of this also, and misunderstandings or inaccuracies in the way that symptomology in particular was being described, being particularly more noticeable amongst those who were not engaged in any kind of TS

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<sup>24</sup> In this quotation, I made the choice to include the vocal tics within the transcription to further illustrate the point being made about unfamiliarity of vocal tics as a symptom of Tourette Syndrome, or as a ‘tic’, despite experiencing them herself.

<sup>25</sup> Diagnostic and Statistical Manual of Mental Disorders 5<sup>th</sup> Edition

<sup>26</sup> International Classification of Diseases 11<sup>th</sup> Edition

support group. Considering that multiple participants stated that knowledge sharing and seeing others' shared experiences in online support groups gave them comfort and understanding of the condition, this is significant to consider here. Bella talked of this sharing of knowledge and best-practice in saying that online support groups are full of people asking questions and sharing what works best for them when it comes to *living with Tourette's* (Bella, Interview 2). Lizzie also shared her lack of experienced support after diagnosis, being told that there were "no support groups" in the UK for her to learn from (Lizzie, Interview 1). These examples, along with the case of Kacy sharing that it took multiple degrees-worth of studying to be able to understand Tourette Syndrome, these online communities prove important not only in providing a sense-of-belonging but also in terms of education and understanding of Tourette Syndrome as powerful in improving wellbeing.

The digital shifting in support group precision and facilitation in the case of Tourette Syndrome is representative of the distinctive Tourettic importance of sense-of-community and belonging. The disproportionately increasing loneliness amongst the Tourettic community as a result of stigma, misunderstanding, and lacking of physical support groups results in this continuation of support seeking that happens beyond the physical. Whether regarding coming to terms with disabled identity (Ricki, Interview 1); not feeling like the odd one out (Yebby, Interview 1), or feeling that nobody would believe their experiences (Madge, Interview 1), the disproportionate loneliness experienced within the Tourettic community, alongside limited and inadequate in-person support, has led to this shift towards turning to online spaces when seeking support. These online platforms have the potential to offer wonderful opportunities for knowledge production, solidarity sharing and broader community-building. It is with this in mind that we must begin to consider the processes of online support group facilitation moving forwards. A large part of this relates to the distribution of power in these spaces – Tourettic voices seem to be considered much more easily here. To return back to the concept of kin-building once more here, there seems to be significantly greater discussion of welcoming experiences of online spaces that are free from pressure and that can be productive in their knowledge sharing ways. Kin-building takes place in public spaces and is deeply connected to spatiality and locality (Gillespie, 2000; Kuper, 1982) and this is inclusive of the digital. In public social media spaces where *anybody* can interact with content

published by the user, kinship can form in and amongst *the likes*. Support networks and kinship are able to be facilitated in these spaces too (Wade, 2019). Online spaces can be created by charitable organisations, yes, but they can also be created by any user of said social media site, whether Reddit or Facebook (as two examples). There is something important to consider in how these hierarchies of power operate within digital spaces, with questions over who becomes facilitator and how they become facilitators also.

### 5.3.1 Creating and facilitating support groups: power dynamics and workloads

Aside from seeking out online community or support for Tourette Syndrome, there were a handful of participants who shared their experiences of creating or facilitating their own online groups. These groups came to exist in a variety of ways, but all came out of a place of *lacking* in terms of something being *not-quite-right* or *uncomfortable* about the spaces that already existed prior to the creation of the *groupgroup* – and therefore a lacking regarding the building of community. Edward shared with me how he used to organize a Yahoo Group prior to Facebook groups as a function being launched:

*Well, for about 10 years – and this started long before I got on the Facebook – in July of 2000 [...], I created a Yahoo group a long while ago, because they don't exist anymore. But I created a Yahoo group called [group name redacted for anonymity], and I headed that up for about 10 years, and then because of creative differences with a member that, well let's just say that he had betrayed me and I trusted him to keep the group equally where we do equal things with is, since it was my creation and he ended up taking the reigns and taking control, and diminishing me to basically just a member. So I got out of that, and I've got to looking on Facebook for faith-based Tourette groups, and that's when I found [group name redacted for anonymity]*

- Edward, Interview 1

According to Edward's account, since the year 2000 – and likely beforehand – online groups have been created to fill the gap of physical and in-person support groups. His faith-based Tourette Syndrome support group(s) are important to him in allowing a sense-of-community with other Tourettic Christians around the globe. After deciding to leave the organizing role of his Yahoo group, Edward was able to find appropriate support and belonging in an online support group hosted on Facebook. These groups are still being created and the need for the continued creation and facilitation of online groups was shared with me by multiple participants. In an interview with Sugar Tits, she shared with me various frustrations over how negative of a place online groups were to her and

expressed a want for a space that focused more on Tourettic “success stories” (Sugar Tits, Interview 1). Whether because of organisers falling out, or frustrations over negative spaces engaging with these groups clearly do not inherently result in the creation of a sense of belonging. Reasons vary but all tie into this sense of belonging, or lack of it, and require us to think beyond digital community and towards an un/community or un/belonging that can occur in these spaces.

Othring or un/belonging can occur not only through exclusion, but also through the act of being given facilitation roles. Feelings of unbelonging can be produced through the additional labour expected by Tourettic people involved in community building and facilitation work. For River, he found himself thrown into the responsibility of facilitating a Zoom support group that met regularly, which used to be run by a large Tourette Syndrome awareness charity in the UK:

*The positives for me are the Zoom calls where we just chat and don't have to explain our tics... it's just chaos and we kind of bounce off ~~each other~~ reach other and it's just okay... [but] having the Tourette's support group that's not monitored by anyone is really hard because there's some really distressed people and like we don't know how to support someone who is suicidal or something. Like, there are some people in some dark times. Currently someone is homeless and we can't do anything about it, but also the charity [we inherited the group from] haven't helped either.*

- River, Interview 1

River came into facilitating the group due to funding being cut by the charity for the running of adult-specific support. This is a group that meets regularly via Zoom, and River still finds value in it as a space that offers support through the sense-of-community and belonging encouraged by engaging with it. It is a group whereby he feels able to tic freely and to do so without feeling pressured to provide an explanation. This is a stark contrast from the aforementioned account of River's regarding people being removed from the TS support spaces (by the same charity in question who previously facilitated the Zoom calls) due to specific symptomologies and shows the value that these online spaces can hold when facilitated and run by experts-by-experience. However, it is key to consider that despite the overall enjoyment and value that River finds here, he also ends up partaking in the additional emotional labour of being the support-giver; this switch from support seeker to support giver occurs not only in physical groups, such as through Leesh reassuring the parents of Tourettic children, but also in online spaces. Engaging in

these groups is, evidently, work. There is a lot of work that goes into engaging with groups, such as the energy it takes to not be too upset with the frustrating negativity in groups, as per Sugar Tits' account, or through navigating encounters of suicidality and homelessness as per River's experience. This additional labor done by Tourettic people contributes to feelings of unbelonging in significant ways, and this includes the additional labour of switching from group member to group facilitator and the shifting power dynamics that come with that. River's shifting role from group member to group facilitator resulted in shifting power dynamics, whereby now he is expected to be the one dealing with suicidality, homelessness, and other emotionally taxing scenarios of which he was not expecting. This is all whilst the group acts as a space for his support, also. Switching between facilitator and general group member means that his identity to others within the group is not fixed. This results in the need to perform in specific ways depending on whether he is acting as a support giver or a support seeker, which in turn contributes to the additional labour not just required to have this dual identity, but also to simply allow this space to continue to exist. These links between hierarchy, group roles, and additional labour all significantly contribute to the *othering* that Tourettic folk who find themselves in facilitative roles might experience.

#### **5.4 Beyond digital community and sense-of-belonging**

This chapter so far has explored various failures and inadequacies found within *in-person* groups in particular, whether in the assigning of a 'Tourettic pariah' role (Leesh, Interview 1), the exclusion of certain tourettic presentations and specific manifestations of tics (River, Interview 1), or otherwise. Evidently, digital spaces are important for many Tourettic people and can offer solutions to many of the concerns that participants have surrounding in-person spaces of support or community-building. However, it's important to also consider the experiences of those who do not engage in these spaces to the same extent, if at all. Whilst the majority of participants discussed positive experiences of online support groups and community spaces, the negative experiences also came through strongly, particularly surrounding hesitancy and concern when it comes to engaging with these spaces. For some this might be due to the additional labour involved, as discussed by River, but this concern can be due to a variety of reasons. This section outlines and further explores some of the experiences that may move us towards a more nuanced consideration of the processes of un/belonging that occur within these digital

public spaces, be it support groups or social media sites more generally speaking. Negative dynamics in online spaces are well recognized within the literature more generally speaking (Alhaboby *et al.*, 2016; Dobransky & Hargittai, 2016; Tsatsou, 2020) but there are perhaps some experiences that were shared with me that could be argued to be distinctive to the Tourettic experience.

The encounters occurring within online support groups can contribute to the unbelonging process of Tourettic people of which the group was originally designed to support. By unbelonging, I wish to create a distinction between *alienation* and the processes I argue to be happening here. These spaces were originally designed with Tourettic people in mind, and so there is an assumed belonging in those spaces. Certain instances and experiences push people away and hinder this sense-of-belonging, but it is also still expected by organisers that those who are being pushed out *should* remain in these spaces. A term like alienation, however, might imply that the Tourettic person is being gradually less connected from the group (sometimes entirely), with organisers not wanting them to remain engaged and active. Returning to the interview with Sugar Tits, she shared with me her frustrations with online support groups, and how she suggests that people take what is found in them with a pinch of salt:

*I do think that the online groups are all a bit fucking negatively... well, they air on the side of negativity, and it's all about "Oh, my poor baby it's so, so hard to watch him" and I'm like why can't we talk about the fact that he was ticcng like fuck and he ran the fucking relay race and got the ribbon at the end? I want success stories! I see enough dross on every other page, but it's like we can't... you've got half the population in these groups who want to center on victimhood mentality. And half of the successes that are the winners. We can all be winners, but do we have to congregate and be Debbie-downers all the time? So... I take these groups with a pinch of salt. I just think "Oh fuck this" and scroll on.*

- Sugar Tits, Interview 1

Sugar Tits is evidently frustrated at the perceived negativity in online support groups. She understands that there are limitations and feels some kind of separation from people in the group who are being 'Debbie-downers' in place of sharing success stories. When referring to the 'oh, my poor baby' narrative had by parents of Tourettic children in these spaces, Sugar Tits taps into something significant in showing how these Tourette Syndrome support groups, much like their in-person counterparts, often end up being

primarily for non-Tourettic parents and carers of Tourettic young people. In a similar way to Leesh's experience of unbelonging in physical support groups, Sugar Tits resultantly feels distant from online groups, creating unbelonging within the digital space. Further to this, in an interview with Adrian, he shared that:

*I think I'm a part of a few groups for Tourette's but I'm not that active in any, and [the Facebook group that we are both in is] the only one with Tourette's I'm in. I don't really use Facebook anymore, but when I did that was [all I used it for].*

- Adrian, Interview 1

In discussing support networks and groups that Adrian was a part of, he shared with me that whilst technically a member of an online Facebook support group for adults with Tourette Syndrome, he does not engage with it very much. Upon further inquiry, he shared with me that he joined this group after being encouraged to do so by somebody who he had reached out to, of whom he knew due to their recent appearance in a documentary on television. He went on to share:

*I wasn't looking for [a group] or anything, and I think [at that point] I didn't mind raising awareness for it [but] I was still embarrassed and ashamed of [Tourette Syndrome] to a point where I didn't want to be associated with any communities or people with Tourette's, because I still didn't want to think about it, you know? [...] So yeah, in some ways I think the group probably helped quite a lot*

- Adrian, Interview 1

What is of particular interest here is the fact that Adrian felt comfortable raising awareness through creating content to be shared widely on social media platforms such as Facebook and TikTok, but that there was something about these existing groups that he felt uncomfortable with. There is a kind of distance, or unbelonging, felt by Adrian in that he felt more comfortable not engaging with groups for Tourettic people in this instance. It appeared that engagement in social media content creation allowed him to stay connected to the Tourettic community, whilst still keeping a perceived distance. There seems to be a tension about being defined by participation or membership in these support groups, which echo broader literature on stigma and disability (Grue, 2016; Nario-Redmond *et al.*, 2013; Watson, 2002). This discomfort surrounding support groups did come up multiple times during the data collection phase. One example that stands

out in particular can be found in Bri's poem, which was featured in the final collaborative zine, *Tic Tic Boom!*:

### **Communities**

*My communities, you inspire me to write.  
Throughout all the different pains and plights,  
Invading my mind day and through the night  
Thinking through solutions to our dire plights.*

*It is not just the plight or yours or mine –  
It will for us finally be fine  
Problems for us all will in time decline  
This I keep thinking in my mind of mine*

*Now you may wonder why it is I care,  
Why do I feel that my voice should be aired?  
For those whose ears are not yet aware.  
For those whose voices are not heard or cared.*

*Now I must away with a heavy heart,  
Remember communities whilst apart.*

- Bri, Extract from *Tic Tic Boom!*

Bri is a queer and neurodivergent young adult with Tourette Syndrome based in the north of England and is engaged in online Tourette Syndrome support groups. In this poem, Bri is referring to online support groups and networks that she finds herself in. When following up on this piece with Bri in an interview, she shared:

*[I wrote this] because sometimes you have to take time out [... ] stop engaging with people with Tourette's as much. Like, I still talk to my friends, but I wouldn't talk to them about my Tourette's and that sort of thing. Not go into the groups, not like posting on Facebook or writing a comment or anything [...] It's hard to just turn it off for a bit, and I want to stay in the communities, but I have to do it for me sometimes because sometimes I get a bit overwhelmed by it. Like all the parents asking all the questions, it's a bit like... [sighs]*

- Bri, Interview 2

It is clear to see here that Bri is echoing the importance of community for her that others have shared throughout the chapter thus far. However, she touches on an important element of people's experiences of these online groups, which is hesitation and concerns over them. For Bri, the above poem highlights how important community is to her – the idea of leaving the community is something that causes significant emotions of sadness, with her describing herself as having a 'heavy heart'. Elaborating on this, in the interview she spoke to me about how she doesn't want to have to leave these communities, whether through putting notifications on mute or leaving an online group all together, but feels that she needs to due to "all the parents asking all the questions" Here, Bri touches on the infiltration of Tourette Syndrome spaces by non-Tourettic people, in a way which echoes Leesh's concerns about physical support group experiences she's had before. It is important here to clarify how this chapter defines 'infiltration' in regards to these support groups, for the sake of clarity. These groups are set up with the primary intention of supporting Tourettic people, with the primary audience being Tourettic publics, ~~so to speak~~. However, what often ends up happening, and what Bri refers to here, is that the focus of support shifts due to non-Tourettic stakeholders coming into the space to find out ways of supporting their children, for example, who might have Tourette Syndrome. This leads to communities of non-Tourettic stakeholders being created, and often they end up being the ones who occupy and are the most visible or outspoken within the context of these support groups. What occurs as a result is that these spaces become not necessarily more closed-off to Tourettics, but rather more *othering*, which in turn pushes Tourettic people away from feeling a sense of belonging within the support group space. This means that the way Tourettic people feel the need to navigate them is similar to that of the largely ableist physical public spaces discussed in Chapter 4. It means that strategizing and careful planning of interactions, trying to pass in certain modes of Tourettic existence, and so on are all practices that occur even in these digital spaces initially designed *for* the very people that end up *doing* the strategizing.

The example of in-person adult support groups actually being directed towards ~~parental~~ ~~parents~~ support raised earlier in this chapter is something that contributed to the migration to online support spaces, but it is evident that there are still instances of this infiltration of sorts into these safe spaces that occur online too. This contributes to

the aforementioned feelings of distance and unbelonging for Tourettic people who are trying to seek support. Others referred to frustrations of seeing people post videos of their children ticcing (and clearly in pain), and unfortunately this seems to be a common occurrence based on the data collected. In fact, this was something raised by Leesh too. Leesh is a Tourettic social worker and mother living in West New York, USA. In an interview, she said:

*I'm part of the Tourette Memes group or SubReddit, but what I like about the Facebook groups, because I don't really like Facebook that much in general, but groups are part of what are keeping me on there in that they're more private and that you can feel a little bit more like you know who you're talking to versus the... if it's kind of a more embarrassing issue you can certainly go on Reddit and I have a little more anonymity but on Facebook it feels a little more personal [...] I feel like in general if it's somebody looking for support, I'm more likely to reply on Facebook and kind of be the helper figure, whereas if I'm looking for help I'm more likely to do it in the more anonymous way.*

- Leesh, Interview 1

For Leesh, there is something about the slight separation from community members that communities based on Reddit<sup>27</sup> offer that speaks to her in terms of increased comfortability in sharing more 'embarrassing' issues and asking more personal questions. There is a sense of control in the level of anonymity that certain online spaces offer that are significant in allowing people to feel comfortable – a comfortable level of distance in some instances seems preferable. The ways that community is enacted in different online public spaces mirrors that considerations of physical public spaces. Perhaps the strategizing work that goes into managing chance encounters feels easier in these digital spaces? Perhaps distance from specific communities, then, does not necessarily equate to feelings of unbelonging, but rather offer a powerful potential for anonymous involvement in the Tourettic community more broadly speaking. This sense of belonging can be found in the more general feelings of belonging within the Tourettic community, just in the same way that people can feel a sense-of-belonging within a specific online support group. However, this then also means that these processes of unbelonging can occur in both. The processes of un/belonging might look like not

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<sup>27</sup> Reddit is a social media platform that plays host to a large number of group forums in which people can discuss any topic they wish. Topics might include art, technology and literature, and can also be not-safe-for-work (NSFW) topics that might concern sex, for example. The company describes themselves by saying that there's a community for everybody available on Reddit.

believing group members' stories and being removed from groups, such as in the case of Madge, or even in the tensions of divisions between people with or without specific symptoms such as coprolalia.

One interesting thing to note here is that in our second interview, Bella discussed the in person Tourette Syndrome group she shared positive experiences about previously. Following this, she moved on to discuss the sense-of-community she feels within the *Tourettic community* more broadly speaking, comparing it to her experiences of being transgender and queer, and a member of the LGBTQIA+ community more generally.

*There's no competing in who's got the worst Tourette's [...] A lot of communities communities are like that and I think, and I've said this for a long time, but the Tourette's community is the tightest, most honest, supportive community I've ever been a part of. It's a privilege to be a part of it. A privilege. The LGBT community – as you know first-hand – there's a divide in the community. Some people think they're more trans than other people... No! If you're trans, you're trans. Who cares? [Some communities I am a part of] are horrible, and then I come to the Tourette's community; the community where everybody loves each other. The community where everybody struggles in their own ways but still recognises that they're not the only one going through it. It's the community where people will travel from one side of the country, just to go to [a support group meeting they heard about online].*

- Bella, Interview 2

Bella's experience of Tourettic community is evidently one that is powerful and impactful for her; she feels well-supported and valued for her individual lived experiences as a trans woman with Tourette Syndrome. However, she then goes on to compare this to her experience of being a member of the LGBTQIA+ community, particularly in regards to her identity as trans. However, it is important to acknowledge that whilst these groups can be incredible in fostering connection and support in online spaces and even more broadly within the Tourettic community, as per Bella's experiences, they are not void of any risk. This risk might be in encountering *too much* negativity to the point of having a negative impact on mental health, or to a point of feeling like a break needs to be taken from the group (Sugar Tits, Interview 1; Bri, Interview 2). This is important to acknowledge as whilst attitudes towards online spaces seem overwhelmingly positive, there is still the risk for negative chance encounters to occur.

Bella's positive accounts of online support groups for Tourette Syndrome and of the Tourettic community more generally speaking – in referring to how people travel across

the country to find in-person community – are strong and speak to strong, significant feelings of acceptance. However, it is important to acknowledge that this sense-of-community was not so strong across the whole sample, particularly in the accounts and ~~experiences~~ experiences of global majority ethnic participants involved in the research. Nesta, a mixed-Black, Caribbean and Asian young man living in the UK shared with me some specific concerns over attending in-person Tourette Syndrome support groups:

*I think I'm sometimes a bit apprehensive about going to groups with people with Tourette's because I don't know what tics they'll have and I don't want... even if I know it's a tic I don't really want to hear racial slurs and things like that.*

- Nesta, Interview 1

Whilst earlier in his interview, Nesta stated that “It would be good to meet others” after sharing that he didn’t know anybody else with Tourette Syndrome and that I was the first he’d had a full conversation with who had a diagnosis, his apprehension was specifically in the potential for hearing racial slurs in a physical group despite knowing that it is an element of coprolalia. Here, he expresses concern about coprolalia and this symptom of Tourette Syndrome being something that would be triggering for him and that would make him feel uncomfortable. Despite knowing that a racial slur that comes from coprolalia does not necessarily mean that the individual ticcng the slur is racist or trying to offend him, he expresses a very significant and influential concern that is not considered within existing Tourette Syndrome literature. What is important to acknowledge here is the difference between physical and online spaces in relation to the controlling of chance encounters that may happen. Whilst a Tourettic individual might be able to suppress tics, coprolalia as a symptom still occurs and is often something that people find difficult to suppress or mask in comparison to other symptoms (Djebara *et al.*, 2008). In online spaces such as a support group, this is an element of the chance encounter than a person might be able to control. Coprolalia affects ~10% of the Tourettic population (Centres for Disease Control and Prevention, 2023), but these ticced obscenities can also have a textual manifestation, whether through writing or through digitally messaging, and this is known as coprographia. However, there is a significant lack of statistically significant data on this, and it is perceived to be less common than coprolalia (Franklin & Teive, 2021;

Singer, 1997). Due to its lesser commonality, Nesta later expressed interest in joining an online Tourette Syndrome support group that he was then signposted to, as it was a way of finding community that had a lesser perceived risk for this kind of potentially triggering and traumatic encounter for him. However, it is key to acknowledge that there is still an element of risk due to coprographia in this instance.

This (perceived) heightened sense of control over chance encounters occurring when using online spaces was also referred to in a positive light [through](#) the discussion of the move towards more common remote working practices since the outbreak of the COVID-19 pandemic. These online working spaces, such as video-conferencing and collaboration tools such as Zoom and Microsoft Teams, began to be used in more social ways during the pandemic. People began to arrange movie nights, games nights, and go for 'drinks' virtually, and the same went for the facilitation of support services. The digital architecture of platforms has a significant role in fostering communities and sense of un/belonging. Following a reduction in COVID-19 restrictions, these online social spaces began to become less common. However, they remain popular in the work-place and in online support services for Tourette Syndrome to this day. For example, Bella stated:

*I quite like online spaces. I love Zoom and Teams [...] Not for their stability, at all... But I love them because I've got a mute button. I can listen without interrupting because of my tics. I can listen and join in without disrupting people. I can't do that in a meeting room or a training room, but I can do it online and that's why I love it. [When I'm in an office...] having to explain it all, them having to get used to it, me every time I squeak or tic when someone's speaking, and everyone's head just looks at me 'cos I've made a noise. It's... that's tough because then you want to suppress more, and the more you suppress then the more it has to come out again and yeah. It's a cycle.*

- Bella, Interview 1

Here, Bella clearly explains that video conferencing software such as Zoom and Microsoft Teams allow her to feel more comfortable in a workplace environment; she talks of how usually being in this form of public space would cause her significant stress due to people turning around and staring at her in response to ticcing, or through feeling the constant need to explain why she is making the noises associated with her vocal tics. However, the ability to stay on mute during video calls (both in a professional and personal context) allows the limiting of potential chance encounters that might *other* her as Touretic (as discussed in Chapter 4). Whether this be in the pressured disclosing of a

diagnosis of Tourette Syndrome, or in the act of staring at the Tourettic person, these are significant in influencing the experiences of othering that are had in various public spaces. Given that camera, microphones and so on can be turned off, these examples of digital software can enable digital publics to feel more comfortable and, in some cases, increase accessibility for Tourettic people.

However, there were also some limitations of video conferencing platforms such as this, including Bella's concern over knowing everybody will be looking at her after she takes a minute's break by turning the camera off, as if they're looking for her 'next move'. What Bella refers to here is one of multiple ways in which the features of these platforms shape the given space and therefore influence the encounters that are possible within it. Whilst Chapter 5 nodded to the physical aspects of public spaces that may influence encounter, such as flickering lights and echoey rooms, here we refer the digital architecture or the user interface (UI) of digital spaces and platforms such as Zoom and Microsoft Teams as key in influencing possible encounters (cf. Appen & Stephens, 2017; Mirsch *et al.*, 2017). In this instance, when Bri turns her camera off in order to provide herself a break, she feels more free to tic. This barrier of privacy, at the surface level, is positive in that it allows the minimisation of negative reactions to obvious motor tics and minimises the felt need to suppress. However, Bri raises an interesting point about how this doesn't solely eliminate risk, but rather shifts that same risk in new directions in that the noticeable absence of Bri's camera leaves people wondering what is going on behind this barrier of privacy. Instead of removing anxiety surrounding this situation, those who know Bri might be thinking about what tics she might be hiding; those who do not know about her tics might be wondering why a camera keeps turning on and off. In either scenario, the return of the visual in Bri's camera being on *adds* to and affects the moment, creating new pockets for interaction and encounter, almost as if an individual is physically leaving and entering a room and causing some form of disruption.

Deciding whether or not to leave a space, such as in the example Bella mentions above, is an intentional and thought-out act of curation of the space in question. The way that Tourettic people curate these spaces varies, but are all significant to consider. Similarly to Bella, Lorna referred to not only the act of muting or turning off the video camera, but of leaving a Zoom call:

*Tourette's Action do a Zoom every Thursday. I do hop on those and when I can, and as and when I feel like it. The problem with being on the Zoom is that with the last one I was on, we had an influx of new members and so you've got usually about 7 and 10 people on the Zooms. Anyway, this one particular day I thought "Oh I'll jump on as well" and we had an influx of 5 new people, which is great, but then you've suddenly got 20-odd people on Zoom with Tourette's. Chaotic was not even the word [...] Yeah, so I didn't stay on that long and it took me so long to calm down. I was like "yeah, I might not [go so regularly if it's going to be overwhelming for people]."*

- Lorna, Interview 1

This should be considered an attempt at curating the space, as Lorna refers to leaving the call because it might be overwhelming for her, and therefore it is likely the case for other people too. Lorna is aware of the overwhelm that others might experience, just as she does in these situations where it takes her a long time to calm down. Whilst Bella refers to muting or turning the camera off to curate the digital space in a way that means she is perceived as less disruptive, Lorna goes a step further in leaving. In fact, she discusses another step beyond this curating act too:

*[W]e do run Zoom every other day, so like the main Tourette's one and then we've got one for daily use and then on the Discord we'll just put "Does anybody fancy a Zoom?" for whatever reason and then we've got a separate sort of link for it [...] The discord is specifically for adults with tics or Tourette's, so not parents and things looking for support I suppose. That's because there's already just so much out there for parents like with what Tourette's Action puts forwards. What we've noticed is that as adults, once you hit 18 you kind of disappear off the face of the earth when it comes to services and support. We had this discussion because they took away the Zoom for about 6 months, and it's kind of a lifeline...*

- Lorna, Interview 1

Lorna here discusses how the members of the Discord server have a specific Zoom link that they use on an ad-hoc basis. This will likely minimise the number of people in the space at any one time due to the fact that they are not necessarily planned in advance and are somewhat spontaneous. In theory, this means that few people attend and fewer people are there to trigger other people's tics, and therefore the space does not necessarily feel so overwhelming. It is also interesting to note that this is only possible due to its separation from Tourettes Action's Zoom calls in this instance, which are hosted on a regular schedule – this ad hoc Zoom space is hosted by the discord members themselves, rather than the Tourettes Action charity. Having this control over allowing it

to stay informal, but still consistent in its accessibility that is not reliant on charity funding and facilitation, is a way of curating a space that somehow feels regular, familiar and safe despite its ad hoc nature. This is particularly similar to the coping strategies and strategic management of chance encounters that have previously been mentioned – curating and managing these spaces is vital.

Another curatorial method that was mentioned by participants in this regard was in regard to the disclosure of tics and Tourette Syndrome diagnosis. Both River and Ricki discussed the act of disclosure as a method of curating these kinds of spaces in a way that aimed to reduce negative or awkward encounters that might come from people not knowing what a tic was. For River, he referred to not needing to disclose in Tourette specific Zoom calls, but about how in his Dungeons and Dragons group<sup>28</sup>, he would disclose as a method of curating the space:

*So we have the Tourette's Action Discord server and Zoom call, so on those specific servers I don't need to disclose that [I have Tourette's], because everyone has tics. But, on other servers, because I use Discord a lot for other socializing because I'm disabled and can't leave the house... when I'm on a voice chat, at the start I'll just be like "I have Tourette's guys" [chuckles] so like I told my D&D group and they were like "Oh that's really amazing, you should incorporate it into your character"*

- River, Interview 1

Similarly, Ricki talked about disclosing diagnoses of tics and Tourette Syndrome in these video based spaces too:

*I guess the other online space that has been really important to me is, throughout the pandemic, my friend group kind of cohered around a weekly Zoom call that we did every Friday for the whole of the lockdown, where we would like chat and do drinking games, and get stoned, and watch movies together and stuff like that. So that was a space where my friends kind of cohered over the last two years, and all of them are very aware that I have Tourette's and I was like very, very open with all the new people that joined our friend group as a part of that.*

- Ricki, Interview 1

In these examples, both River and Ricki show how their disclosure of a Tourette Syndrome diagnosis were important things for them to do *from the outset* of interaction

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<sup>28</sup> Commonly abbreviated as D&D, Dungeons & Dragons is a fantasy tabletop role-playing game that allows each player to create their own characters

within a space or in a new person entering into that trusted space of friendship. Through doing so, the spaces are curated in a way that attempts to minimise potential awkwardness through people asking what a noise was in response to a vocal tic, for example, or in asking why somebody might keep making ‘strange faces’<sup>29</sup>.

These are all attempts to minimise the processes of othering, or unbelonging, that not only occur in physical places but also in the digital realm. This unbelonging and othering occurs to some extent through concerns over forthcoming encounters. This might be in the examples of feeling concerned about future encounters with non-Tourettic stakeholders in a Tourette Syndrome support group, as outlined by Sugar Tits and Bri. It could also be through concerns and uncomfotability over encounters relating to other Tourettic people and how they might tic something that would trigger you, as in the case of Nesta. They can even be facilitated through tools and actions that are specific to online platforms such as Zoom, through concerns over *what happens next* following turning your microphone and camera off, as outlined by Bella.

However, despite concerns and the processes of unbelonging at play, it seems clear that the importance of online support groups or spaces of community building for the tourettic adults involved in this research is significant, particularly when it comes to marginalized groups of global majority ethnics Tourettic and/or trans Tourettic people. It is important to acknowledge the labour of curatorial work that is being done by Tourettic people to minimise the risks of this *othering*, as per River and Ricki’s aforementioned accounts of disclosure as prefacing interaction with these online spaces. There is emotional labour, and oftentimes physical labour in the suppression or picking-up of tics, involved in the process of community building in this case. Processes of othering, or unbelonging, not only occur in physical places, but also in the digital realm such as in support groups, Zoom calls, and so on. This might be in the example of feeling concerned about future encounters with non-Tourettic stakeholders in a Tourette Syndrome support group, as outlined by Sugar Tits and Bri. It could also be through concerns and uncomfotability over encounters relating to other Tourettic people and how they might tic something that could be a trigger, as in the case of Nesta. They can even be facilitated

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<sup>29</sup> These are examples drawn from my own experiences, in lieu of specific reference by these particular participants. By using my own experiences to relate to those of the project’s participants here, I hope to illustrate more clearly this argument.

through tools and actions that are specific to online platforms such as Zoom, through concerns over *what happens next* following turning your microphone and camera off, as outlined by Bella.

As has been explored throughout this chapter, the desire for community is shared by all Tourettic people who participated in this research. Whilst there were hesitancies and frustrations expressed, the desire for community was very much still there as a constant feature of experiences that were shared with me. Whilst already seemingly a rare occurrence, even if diagnosed before the age of 18 and set up in a good support system, once the person turns 18 they end up having to search for other forms of community and belonging. If a diagnosis is received in adulthood, this means that the people in question skip the step of experiencing that support, ~~so to speak~~. In both instances, these individuals seem to seek community at an in-person support group, which oftentimes fails to deliver adequate provisions, or in online forums and community groups on Reddit, Facebook or TikTok.

With this in mind, I argue that whilst online public spaces can offer a sense of belonging, emotional support, and knowledge production, it is important to acknowledge that these spaces have become associated with risky chance encounters due to the othering processes that happen surrounding the Tourettic community. The distinctiveness of Tourettic embodied experiences of public space is therefore not solely in the *requirement* for creative interaction with and strategic management of chance encounters, but also in the deeply interconnected processes happening across the borders of digital and physical to continually *other* Tourettic people. Community is found in unexpected places, such as in online worlds. Schroeder writes:

*“Disabled community teaches us how to weave love in a way that’s hard to put into words. We weave to sustain ourselves, one another, and our shared histories. We send one another threads across time and space. We ship them off in envelopes with letters and postcards. We trade them during Zoom calls where we do absolutely nothing together. We gift them over long phone calls peppered with silence because quietude is love, too. [...] The threads whisper that we are worth everything. That it is worth rebuilding the world so that we have a place in its future. They remind us that our lives have value, even when the world disagrees”*

- (Schroeder, 2024: 14-15).

In the context of hostile and unwelcoming social dynamic, Tourettic folk positioned as different can seek to create community and sense of belonging in a multitude of ways. It is produced and practiced in many varying ways, and leads us to realise that loneliness is not the only option, and that it is more than worth exploring solidarity and how to enact it, and how to facilitate it with one another. Disability intimacy is found in these spaces, and are also a part of the chance encounters that may or may not populate TS spaces. What other spaces might this crip care and solidarity unexpectedly arise?

## Chapter 6. Creative methodological contributions to hopeful futures of tourettic belonging

Within this doctoral research project, creative and collaborative methodological approaches were implemented with the intent to *capture* Tourettic experiences of public spaces in an accessible way. The goal was to make it accessible specifically for a previously unconsidered demographic of Tourettic adults to help highlight the ~~nature of~~ problems surrounding the additional labour required, through the need for continuous creative strategizing when engaging with public spaces (Chapter 4), and the distinct Tourettic experiences of loneliness and isolation (Chapter 5) as identified in the previous chapter(s). The aim was for the *messy* method of zine-making to be used to facilitate the consideration and expression of the messiness of Tourettic experiences. Methods have previously been conceptualised as *mess(y)* such as in Mellor's acknowledgment of unfolding narratives and the jumping between elements of inquiry in sporadic ways (2001), in Sanscartier's "craft attitude" of taking a non-linear, *messy*, approach to research as storytelling (2020: 47), or more broadly as something which is needed in the research of particular groups of people when conducting nuanced and complex research (Eldén, 2012), to name a few. In the case of my research, *mess* might be in acknowledging the mess of creative, strategic management of chance encounters (as explored in Chapter 4), or in the conflicting and interconnected experiences of community building in digital publics for Tourettic adults (as explored in Chapter 5), amongst other previously discussed instances. The *messy* and non-linear nature of embodied experiences that have previously been explored in this thesis are particularly suited to further exploration of these ideas through the layered and non-linear method of zine-making. Given the previous chapters accounts of Tourettic experiences of stigma and isolation, we might ask questions of exactly *how* to share solidarities, build communities, and facilitate sense-of-belonging for Tourettic adults through the use of *messy* zine methods<sup>30</sup>.

This chapter ~~will initially explore~~ ~~explore~~ the value of creative and collaborative research methods in documenting Tourettic experiences. ~~To do so,~~ I discuss a collaborative zine making workshop in which we co-produced *Tic Tic Boom!* By

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<sup>30</sup> Once more, in referring to zine methods as *messy*, I am building on the work of scholars such as Mellor (2001), Fitzgerald et al. (2021) and Eldén (2012) who value *mess* and non-uniformity in methods in ways that creative approaches such as zine-making can contribute towards.

reflecting on ~~and documenting on~~ this process ~~and considering data from subsequent follow-up interviews with zineing workshop participants~~, the chapter seeks to highlight the potential of creative methods, notably zineing, as a means to facilitate solidarity ~~and to consider ingits, considering~~ the importance of ~~solidarity sharing~~ and community-building as key ways in which disabled or Tourettic people ~~use negotiate~~ public spaces. ~~Using creative methods is especially important with~~ Tourettic ~~people~~. Many tourettic people ~~have experienced trauma and substantive stigma~~, and this highlights the need of safer-feeling spaces to explore this. These are incredibly important, in line with notions of crip negativity, which Smilges refers to as:

*“bad crip feelings felt cripplly. It refers, on the one hand, to the many bad feelings that disabled, debilitated, and otherwise nonnormatively embodied people encounter with some regularity: pain, guilt, shame, embarrassment, exhaustion, fear, and anger, just to name a few. On the other hand, crip negativity names how these bad feelings are felt: deeply, slowly, tearfully, fitfully, sleeplessly, suicidally, hungrily, among the long list of excessive and pathological ways that crips feel” (2023: 8).*

Whilst crip negativity is important to consider and has been addressed in previous chapters, I believe that it is key to move now towards a more hopeful future – to refer to the title of one subsection within this chapter. These hopeful futures, unlike the phrase might suggest, require attending to one of Smilges’ key arguments in that the useless, bad crip feelings are incredibly valuable, and with this value comes hope for the future. This chapter explores the links between Tourettic hopefulness that arises out of the acknowledging of crip negativities, and the practice of community ~~zineing hopeful~~. I explore the doing of ~~zineing this creative method~~ as a means of forging ~~solidarity, and solidarity and~~ consider the workshop design ~~(featuring ethnographic researcher reflections)~~, before addressing ideas of performing body absence/presence and discussing ‘hope’. Inspired from Hall’s (2013) problematisation of *inclusion* and suggested shift towards *belonging* through creative arts, and in line with the focus of Chapter 5, this chapter explores the intricacies of solidarity and community building through collaborative *zineing*.

### 6.1 Situating creative geographies in solidarity

Solidarity has been significantly explored across ~~academic disciplines a range of literature, and many definitions have arisen from published work~~. Solidarity a “feature of relationships between persons.” (Miller, 2017: 61) – a distinct we of sorts that alludes to

mutual aid obligations and a sense of being a group. Ultimately, it is important to acknowledge that “[a] core idea of solidarity is that the group as a whole shares the risks, burdens or possible threats” (Dawson & Verweij, 2012). In the case of Tourette Syndrome, this might be the risks of injury arising from tics, or the threats of simply existing within publics, both physical and digital. Regarding intersectional approaches to solidarity, I share similar concerns to Tormos (2017) who highlights some of the conflicting and contradictory ways in which solidarity is defined, such as through shared interest (Taylor & Whittier, 1998) or through shared identities (Anner, 2019). This research works from the position that solidarity does not necessarily come from shared common identity or ~~interest, but~~ ~~interest but~~ can also be enacted amidst contrasting or intersecting identities, that still offers this distinct sense of we, as per the words of Miller (2017). Working in creative ways, such as approaches adopted within creative geographies as a subdiscipline, can provide excellent ways of doing this. In order to highlight this, perhaps what it makes sense to first acknowledge is the way that we came to design the zineing workshop within this project.

It has been said that geography is experiencing a creative (re)turn (Hawkins, 2019), with geographers developing and deploying different methods for data collection (Raynor, 2019); for research dissemination (Valli, 2021); to enable further public discussion of key themes arising within research (Johnston & Pratt, 2021), and also for teaching purposes (Jones, 2024; Bagelman & Bagelman, 2016). Ultimately, creative geographies might be considered as “methods of experimental art-full research that have creative practices at their heart” (Hawkins, 2015: 247). With the buzz of creativity amongst some geographers, it is important to acknowledge some of the key discussions happening surrounding creative geographies at present. Veal ~~and~~ Hawkins (2020) urge us to move beyond the fetishization of creativity within ~~geography, and~~ ~~geography and to~~ ensure that we as researchers ~~and academics~~ do ‘due diligence’ and that we ‘practice mindful research’ (p365). By due diligence I mean taking steps to ensure that we do not appropriate the use of zines and zineing in ways the go against the roots of the practice. Practically this looks like planning ahead, being aware of the roots of the relevant method(s) - in this project this considers zineing - and moving beyond this by acting upon that due diligence (the ways in which this was done in this project will be discussed later in this chapter). Practicing mindful research might involve staying aware of ethical issues surrounding

ownership and creative labour; the financial costs of working with artists fairly, or of any 'moment' or 'pattern' that may be occurring in regards to a specific creative methodology or approaches, whether in dissemination practices, research trends, or otherwise (Jones, 2024).

As explored, solidarity is a key element of this research and given that this research is facilitated by a neoliberal academia / academic funding. This is particularly relevant given the neoliberal de-professionalisation or de-skilling of certain practices such as the creative arts, along with a history of exploiting marginalised groups. There were some decisions made that attempted to mitigate these dynamics and ensure that marginalised communities (in this instance, Tourettic adults) were centred. By centring adults in creative art-based methods, the project attempted to push back against the infantilisation of, and the dilution of the value of, creative arts. Solidarity and its value have been central to a significant amount of creative geographical work particularly given the frequent pairing of creative and participatory action research methodologies. Examples of this might include using a variety of multimedia creative activities to enable young people to discuss youth and their connectedness to their local community (Fenge *et al.*, 2011) or even theatre making and character design to imagine social action amongst refugee communities (Kaptani & Yuval-Davis, 2008). Whilst these papers are not explicitly about solidarity, the participatory approach represents researcher commitment to solidarity. Solidarity has been particularly considered around the context of zineing. This is something I argue that we should also be wary of when working within the neoliberal university. The risk of this is the coopting of zines for profit, rather than the community-focused activity of zineing (Jones, 2024). With this in mind, solidarity comes to the forefront of consideration in regard to wider contributions that this chapter hopes to make to the field of creative geographies. In particular, Zines have been explored as ways of expressing complex solidarities that move beyond the hopes and desires of neoliberal funders who wish for creative arts to spread their own names far and wide (Smith, 2012). For example, Schilt (Schilt, 2003) has published about zines being written by a group of globally ethnic majority teenage girls in a way that isn't aimed towards adult audiences as being a useful research tool "because these writings are composed for peer groups and personal use" (p79). The work of the teenagers in question with Schilt's project here assists in the facilitation of community-building within the group, which I also argue to be

a key element of solidarity-sharing as it works to provide a sense of belonging for those community members.

Specifically, this chapter wishes to contribute to the solidarity-focused potentials of zineing through a primarily process-focused lens – something that I argue is still lacking from existing literature. What if the zine was not produced *for* non-tourettic people? What if the focus was not necessarily trying to educate other non-tourettics, but rather offering a *space* for solidarity; a space for community building; a space for hope that lingers in the future, re-imagining a world beyond the bleakness of many Tourettic accounts. As per the work of Jaramillo-Vasquez (2019), what if we consider creativity as collaboration, or at least focused on the collaborative act of solidarity sharing? What might a specific processual lens through which to consider zineing methods reveal? This chapter ~~offers an example that~~ demonstrates the value of process-focused creative geographical methods that centre solidarity.

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Zines are small circulation self-published works of original and reused texts, images which have long existed as a powerful way to share ideas that might not fit neatly within conventional publishing outlets (Piepmeier, 2008; Poletti, 2008; Ramdarshan Bold, 2017; Zobl, 2001). The exploration of zines within geography has gained momentum in recent years, being considered as a pedagogical tool (Bagelman & Bagelman, 2016), research method (Fannin, 2020; Hawkins, 2019), and tool for building complex solidarities (Schilt, 2003; Smith, 2012). Zines and zine-work are thriving within various academic spaces, ~~and this is reflected in the influx of zine-based published research in recent years.~~ Recent published work on zines is significant and varied. Valli's account of interview-based zine-making as participatory method for dissemination (Valli, 2021) and associated commentaries (Bagelman, 2021; Cele, 2021); Velasco *et al.*'s exploration of zine-making as a creative, feminist geographic method for researching imaginaries of environmental justice (Velasco *et al.*, 2020b); and Nash *et al.*'s consideration of co-produced zines in producing knowledges via reflection and collaboration (Nash *et al.*, 2022) ~~are just a few of the notable recent zine-based geographical works. Evidently,~~ There is a strong focus on the collaborative aspects of zines, be it in their collaborative disseminatory potentials or within co-production. However, questions should be asked of how we move beyond being 'sucked in' to the *moment* that zines seem to be having in academia, and what to consider in designing zineing methods (Jones, 2024).

Zines have their roots in solidarity, and as this chapter will outline, there is an argument to be made for a process-based focus on *zineing* rather than zine-making (as final product) that offers us ways to ensure that we stick to these roots. Recent academic work that implements zines within the research methodology significantly focuses on the zine as a final product, whether in looking at research dissemination (Valli, 2021), as community archive filled with these *finished products* (Baker & Cantillon, 2022) or simply as tool for thematic analysis (Watson & Bennett, 2021). Whilst valid expressions of solidarity, and with solidarity being planned within these methodological approaches, more needs to be done that goes beyond capitalist notions of *product*. Zineing, as will become clearer throughout this chapter, does not have to be product-focused. What if we were to focus on spaces of solidarity beyond products, whether in *finished* zines to be sold, or simply in restricting solidarity to the confines of a *finished* booklet – solidarity is an ongoing process. Beyond zineing specifically, solidarity is key to much of the published research that implements *community*-based participatory approaches. Notably, O’Neill *et al.* (2018) speak of the development of arts and participatory methods in collaboration with participants as community based arts methodology, sharing that doing so leads to conclusions that “[a]n aesthetics of process allows movement towards a more complicated and ‘messy’ understanding of community and society that is rooted in notions of interdependence, rather than integration” (O’Neill *et al.*, 2018: 50). The paper shares interesting points particularly about creative workshops and the use of multiple languages as being encouraged, almost encouraging the non-censoring of shared experiences within the space. Across different languages, messy yet insightful understandings about the performance of migrant citizenship across racialised boundaries were uncovered – something that arguably would not have been as insightful if participants were encouraged to stick to a single language. This focus on the process allows for the valuing of *mess*. Creative and participatory methods have long been stated to offer room and the valuing of mess (Cook, 2009; Eldén, 2012; Fitzgerald *et al.*, 2021; Law, 2004; Sanscartier, 2020) but it is my argument that through a focus on product we risk trimming elements of experience off the edge in order to ‘make room’, or to neaten things up for viewer/reader comfortability. I have argued this to be the case elsewhere (Jones, 2024).

Designing research methods has never been a simple, surface-level activity (see chapter 3). Advanced-level research methods courses teach key considerations to take into account regarding onto-epistemological approaches to our research, and the sheer existence of ethics as a field of study highlights the complexity of methodology knowledge production. A significant part of this research's methodology ended up being in the zineing workshop facilitated at TIC-Hull, of which was attended by 6 participants from the project. As discussed, the project was designed in a collaborative manner, with focus groups of participants and with the charity TIC-Hull (all those involved in the design of the project have a diagnosis of Tourette Syndrome themselves).

Zineing ~~must can~~ be considered more than a dissemination tool. Zineing has the potential to be a research tool *and* mode of collaboration that not only allows for solidarity sharing, but actively encourages it. ~~I~~; the process of how we work collaboratively is key in thinking about the solidarity-centred roots of zine making, particularly if we as academics are careful not to co-opt them under the neoliberal university agenda. The chapter now turns to discussing zine making with participants at TIC Hull. I start by narrating the design of our creative workshop, which hoped to ~~The focus being taken in the design of the workshop was always accessibility, comfortability, and an opportunity to creatively explore participant experiences of Tourette Syndrome and public spaces. The workshop was designed in a way that we hoped would result in the capturing~~ Tourettic lived experiences in the form of a zine. However, due to the way that it was designed, planned and facilitated in the end resulted in the capturing of Tourettic experiences not necessarily exclusively in the form of a zine, but in the form of reflection on the workshop space itself.

## 6.2 Designing solidarity-focused zineing methods

I worked closely with a North-East based zine artist Zeke Woodley<sup>31</sup> to both design and facilitate the ~~workshop with participants at TIC Hull session; W~~we were offered funds for the workshop and this included a set amount specifically available to be used towards paying facilitators and zine materials. The money came from member contributions and efforts to raise money for the charity during the previous Tourette Syndrome Awareness Month ~~in (2021).~~ As a ~~funded~~ PhD researcher ~~who was funded~~, I decided that it would be

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<sup>31</sup> Zeke Woodley is a pseudonym that has been used at the request of the zine artist to protect their identity.

unethical for me to be paid for facilitation of this session, ~~and this is why I reached out specifically to Zeke.~~ Zeke is a trans-nonbinary zine artist from the ~~North East~~ Northeast of England. Zeke does not have Tourette Syndrome but is somebody who I had worked with in the past and who had plenty of ~~creative facilitation~~ experience ~~facilitating spaces where the participants were the focus, than.~~ Ultimately, ~~I considered~~ Zeke ~~was somebody who I trusted, as somebody with Tourette Syndrome myself, as~~ an ally and as somebody who understands how ~~to build and facilitate~~ ~~solidarity, solidarity works in the way that this chapter defines it.~~ ~~T~~—the involvement of a non-Tourettic facilitator ~~will be discussed becomes later particularly important context for forthcoming discussions~~ in this chapter. Allyship is a complex term that has been significantly discussed (Brown & Ostrove, 2013; Kluttz *et al.*, 2020; Sumerau *et al.*, 2021), but we worked with Lilla Watson’s understanding of allyship as:

*“If you have come here to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, then let us work together”*

(2020: 49).

As an LGBTQ+ activist, Zeke’s own liberation (shared with my own as a member of the LGBTQ+ community) is deeply intertwined with that of the liberation of disabled, neurodivergent, and chronically ill people’s. This consideration of intersectional allyship and identifying of Zeke as a trusted ally, who is familiar with intersectional liberation, and the fact that a significant proportion of the project’s zineing workshop participants were also members of the LGBTQ+ community meant that Zeke, for me, was an important person to have on board with the project in this workshop facilitation role.

~~Contextually,~~ It is ~~also~~ important to acknowledge the source of funding for the running of this workshop. ~~The funding~~ Funding ~~came~~ via ~~the~~ fundraising efforts of TIC Hull members. TIC Hull were not explicitly clear about their expectations, stating that they were simply happy to fund the running of the workshop session itself, without prescribing specific desired outputs. This means that the charity themselves, consisting of non-research staff (and non-Tourettic people), also had some control over the running of the session (though they were very keen for me as researcher and Tourettic person to take the lead and have the final say). The act of taking a step back and not being overbearing, as

such, in determining how the workshop would run, what it would look like ~~and so on~~ was a key ~~as an~~ act of solidarity. This stepping back and giving the power ~~over to a Tourette person~~ was significant in demonstrating their commitment to ensuring this space was primarily by and for Tourette people. Ultimately, at this point in the discussion it is important to acknowledge that this influenced the way that the workshop was designed in that we felt free ~~to~~ organise and structure the workshop in the way we collectively saw fit.

### 6.2.1 Planning the workshop



Figure 3a: A photograph of the front entrance to 'The Hub' at TIC Hull



Figure 3b: A photograph of the workshop space prior to being set up for the session

Key to the planning of the workshop was the site at which the workshop took place. In order to paint the scene in a clear way, I have taken words from my personal research



Figure x: A photograph of the front entrance to 'The Hub' at TIC Hull

diary to illustrate the venue. This section will feature this ~~extract, and extract and~~ follow up with some greater reflections on the planning of the workshop ~~that are~~ relevant to the theme of solidarity.

*I pull up into the car park to be welcomed by a staff member who I've worked with closely, who tells me how excited they are that the workshop is happening.*

*Immediately next to the car park, at the entrance of The Hub, there is a Progress Pride banner that hangs proudly from the metal fence that houses The Hub's patio area (Figure 3a). The banner hangs all year round, other than during Pride marches where members of the charity, service users, volunteers, staff and trustees march with the banner held high as allies and members of the LGBTQIA+ community themselves. Walking through the patio, you turn right into the building. Immediately on your right is a small office with 4 desks, opposite a small kitchenette from which a volunteer immediately offers you hot drinks and encourages a donation. Walking down the corridor, at the end on the right-hand side is a sensory room that has recently been installed. It is where, at a monthly support group meeting, you will find no shortage of sensory-seeking children enjoying the relaxing cycling RGB LED lighting, or the variety of textures on the floor and wall. Continue up the corridor and you will find two rooms that are mirrored in size and shape, a small room on the left-hand side that plays host to a range of children's craft activities throughout the week, and where regular Tourette Syndrome youth groups are hosted on a weekly basis. On the right-hand side room, you can find a naturally lit space with a hodgepodge of mismatched furniture (Figure 3b). The Hub and its rooms have been designed and furnished based on direct feedback from service users; mismatched furniture stopped the space feeling too clean in order to help minimise oppositional tics<sup>32</sup> that might result in coffee stains from thrown beverages in opposition of the cleanliness; there are guinea pigs adopted to facilitate pet therapy at any*

<sup>32</sup> *Oppositional tics* is not an official clinical term, but one that was coined by activist and artist Jess Thom (commonly known as Touretteshero) in an attempt to better outline the experience of coprolalia beyond 'social inappropriateness' as a response (given that the name refers to people's response to tics rather than to the actual experience of *ticking*) (Thom, 2020).

time of day; the Progress Pride banner hung out the front to immediately state that The Hub is a safe space for queer and trans folk.

The combination of social and material elements that make up the atmosphere of *The Hub* is significant in contributing to the choosing of it as a location from which to host the zineing workshop. It was a familiar space to most participants, minimising stressful triggers, and is openly queer and trans-friendly. This was especially important given that the majority of people participating in the workshop were queer and/or trans themselves. In the planning phases of the workshop, Zeke and I met multiple times to discuss what a workshop would look like. We chatted in great depth about what it was that participants of the project at this point had found most interesting, along with some common themes that had come up in initial data analysing and coding. This included ideas surrounding awareness raising, stigma and general experiences in public spaces<sup>33</sup>. Whilst the workshop was designed partly in response to initial interviews and focus groups, the questions and prompts aimed to be as open as possible to allow a wider variety of topics to be brought into the space that were of the most importance to the participants. Awareness raising seemed key, partly in light of conversations surrounding *Britain's Tourette's Mystery* documentary that had previously aired (Firecracker Films, 2022; Jones, 2022), and the ways in which these impacted experiences of public spaces. The workshop was designed and ~~facilitation~~ planned through the production of a care plan for both Zeke and the participants in question (Appendix j), based upon symptomologies, comorbid conditions experienced, specific triggers, and so on. These were collected in both the initial recruitment phase through a consent form, as well as through interviews and through getting to know participants on a more personal level<sup>34</sup> to ensure that I was fully aware of any access requirements to the best of my ability. In this instance, this involved ensuring that a room with ventilation was used; masks and face coverings were encouraged to be worn and there were transparent facemasks provided for those who wanted to use them, in order to cater for participants who were D/deaf, hard of hearing or otherwise relied partially on lip reading. Further to this, based on the sharp,

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<sup>33</sup> Refer to Chapter 4 for a full list of codes for the data.

<sup>34</sup> I have volunteered, attended support groups on a personal capacity, and currently hold a trustee position for the charity board for TIC-Hull. As a result, I have ~~built relationships~~ ~~built relationships~~ with all of the participants who were in attendance of the zineing workshop, other than Bri who had not attended any TIC events prior to the workshop, but was digitally connected with some of the other participants via Facebook forums and community pages.

loud and sudden nature of some people’s tics, a carpeted room was secured for the workshop, which had lots of soft furnishings to absorb sound as best as possible and reduce echoing, which is something that further triggers people’s tics based on workshop participants’ previous interview and focus group contributions. Tables were secured that were tall enough to allow wheelchairs to be pushed under for participants who were unable to self-transfer (or who chose not to); and lighting was soft and natural, with a sense of privacy being retained through the frosted glass on the windows, as can be seen in *Figure 4*. The space was kept as casual as possible, and purposefully encouraged messiness to allow the session to feel less formal (a concern that I had previously had due to the fact the session was being facilitated as a part of an academic research project).



Figure 4: A photograph of the zine workshop, with faces blurred for anonymity.

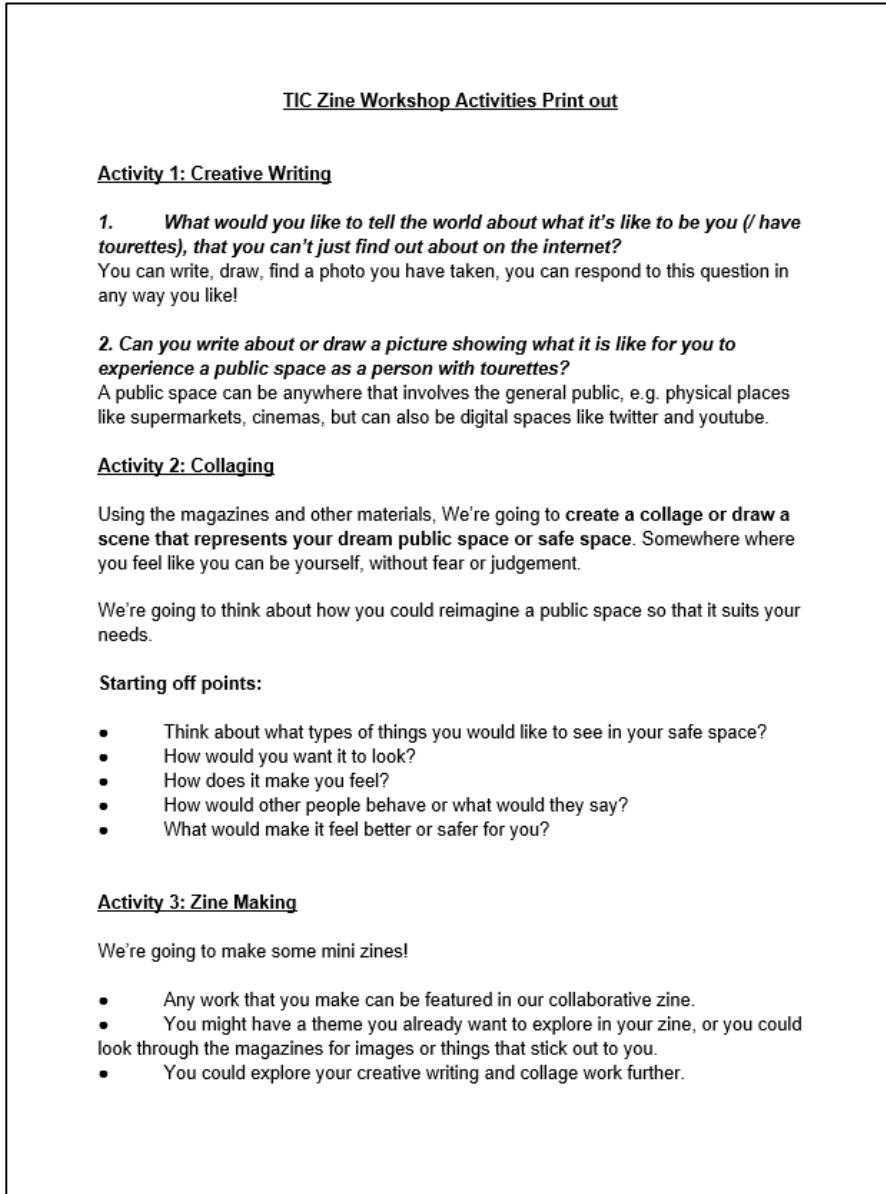
Pseudonym	Age	Sexual Orientation	Gender	Ethnicity	Location	Role
Porkchop	23					Participant
Stacey	22					Participant
Pete	33					Participant
Bri	21					Participant
Bella	33	Homosexual	Trans Female	White British	TIC Hull	Participant
Yebby	20	Homosexual	Cis Female	White British	TIC Hull	Participant

Zeke	26	Queer	Trans Non-Binary	White British	N/A	Facilitator
Selia	23	Homosexual	Trans Female	White British	Online Forum	Carer of Participant
N/A	27	Queer	Cis Male	White British	N/A	Researcher

*Table 4: Demographics breakdown of zine workshop attendees*

Whilst all of the participants were white British, other identity characteristics of the workshop attendees were rather varied, even amongst a relatively small group (Table 4). After acknowledging that whilst the participants were diverse in regards to gender and sexuality but not regarding recruitment strategy or ethnicity, Zeke and I tailored the workshop and its prompts as best as possible. Part of this included wording prompts in ways that suggested the value of intersectional experiences being shared, without using the jargon term of ‘intersectionality’. For example, in the ‘Starting off points’ (Figure 5) we did not specifically mention Tourette Syndrome – the prompt was about experience more broadly speaking and this allowed for the consideration of intersecting identities and their relevance on Tourettic experience. The group was diverse particularly regarding gender and sexuality, which immediately struck myself and Zeke during the planning phase and during the process of putting the workshop prompts together. Intersectional experiences had been raised by participants by this point in the project, and so it was of particular importance to ensure that prompts had the capacity to be responded to in a way that acknowledged the intersectional experiences of Tourette Syndrome that the workshop participants were having. This involved wording questions and guiding instructions in a way that was as open as possible, with no restriction (only optional guidance) for what to include, or in *how* to respond to that also. The final workshop plan (Figure 5) is demonstrative of ~~the~~ the focus on experiences occurring in and around public spaces, with considerations of looking to the future regarding what safe space means, how to improve accessibility, and so on being implemented into the workshop structure. Due to the limited capacity of suitable venues elsewhere in the UK to host additional workshops

with more participants, a singular 3 hour workshop was held. However, the data generated was plentiful.



*Figure x: The finalised plan for the zineing workshop. This image shows the print-out version that participants all received copies of during the workshop.*

To ensure that people felt able to respond to prompts in whatever way they were most comfortable with the workshop and prompts were designed in a way that were able to be open to interpretation. For example, as seen in *Figure 5*, ‘What would you like to tell the world about what it’s like to be you?’ was one of the first prompts for the workshop. From the very outset, we intended to allow for very individualised experiences to be valued within the workshop space. As a result, personal experiences were demonstrated and reiterated to participants as extremely valuable and important, whilst also allowing them to be as specific or as general as they saw fit. Some participants wrote specifically of Tourette Syndrome and statistics in response to this, whilst others were more general in their approach such as writing about the accessibility needs they felt others should know about. Even in the fact that prompts could be responded to in such a variety of ways, it somewhat created an expectation of varied and contrasting experiences being raised within the session, which I believe significantly added to the welcoming space, and contributed to participants’ sense of belonging within the workshop space. Although all participants shared their work, there was never any pressuring to do so. There were regular reminders that people were not obliged to share what they’d been working on, though everybody felt that they belonged in the space and were able to contribute as much or as little as they felt comfortable to. The session also began with wider rule and expectations-setting for the workshop which ensured that the space occurred in a way that was on their own terms, and helped to be designed and facilitated in ways that felt the most welcoming. All of these things greatly assisted in allowing these contrasting experiences to feel safe to explore in this setting, evidenced by the presence of many contrasting experiences being shared and included in the final iteration of *Tic Tic Boom!*:-

## TIC Zine Workshop Activities Print out

### **Activity 1: Creative Writing**

**1. What would you like to tell the world about what it's like to be you (/ have tourettes), that you can't just find out about on the internet?**

You can write, draw, find a photo you have taken, you can respond to this question in any way you like!

**2. Can you write about or draw a picture showing what it is like for you to experience a public space as a person with tourettes?**

A public space can be anywhere that involves the general public, e.g. physical places like supermarkets, cinemas, but can also be digital spaces like twitter and youtube.

### **Activity 2: Collaging**

Using the magazines and other materials, We're going to **create a collage or draw a scene that represents your dream public space or safe space**. Somewhere where you feel like you can be yourself, without fear or judgement.

We're going to think about how you could reimagine a public space so that it suits your needs.

#### **Starting off points:**

- Think about what types of things you would like to see in your safe space?
- How would you want it to look?
- How does it make you feel?
- How would other people behave or what would they say?
- What would make it feel better or safer for you?

### **Activity 3: Zine Making**

We're going to make some mini zines!

- Any work that you make can be featured in our collaborative zine.
- You might have a theme you already want to explore in your zine, or you could look through the magazines for images or things that stick out to you.
- You could explore your creative writing and collage work further.

*Figure 5: The finalised plan for the zineing workshop. This image shows the print-out version that participants all received copies of during the workshop.*

### 6.3 Hopeful Futures in Spaces of Belonging

Through chatting with people involved in the focus groups and advising on the project more broadly speaking, reviewing the data collected at this stage in the project, and regular conversation and planning with Zeke, I knew it was important to ensure that this methodological approach allowed the understanding of complex commonalities to be explored in a safe and supportive way within the session. The workshop began with timed creative activities, as outlined in Figure 6, in order to get people thinking. Following this, in response to workshop prompts participants used magazines and print outs provided by myself and Zeke, along with a variety of stickers and cut out mixed media to explore their answers and their experiences of Tourette Syndrome. Some decided to cut out individual images to make small and detailed responses to the workshop prompts, whilst others more

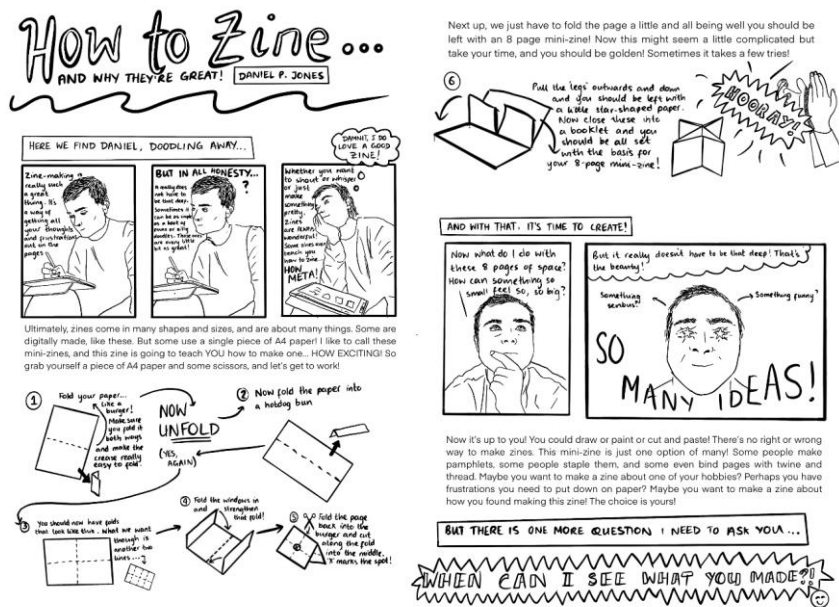


Figure 6: 'How to zine and why they're great' – a guide to zineing made by Daniel P. Jones.

messily ripped the pages out of magazines in an almost cathartic and impulsive way. Some stayed clear from visual material and focused on creative writing, either typed or

hand-written, depending on their preferences and how they impulsively felt to best respond to each prompt. Refreshments such as teas and coffees were provided throughout, and participants were encouraged to head outside for some fresh air, a smoke, or to go to the toilet at any point; the participants were encouraged to engage in the workshop as much as they felt they wanted and were able to. Throughout the workshop, conversations about previous focus groups and interviews conducted came up, and participants shared with each other stories of distress and sadness, but also of enjoyment and hilarity as they engaged in the materially focussed act of creating, or more specifically *zineing*. Notably, participants were given a demonstration of how to make a mini-zine with 8 pages from a single sheet of A4 card (*Figure 6*), and then encouraged to either continue working on individual creative responses to prompts or to create one of these mini zines based on an aspect of their experiences in public space as Tourettic people.

Across the previous empirical chapters of the thesis, plenty of negative and negatively emotionally charged experiences have been discussed, and solidarity expressed through the acknowledging of these experiences here. However, staying in line with Gagliano's (2021) call to ensure that 'solidarity' is not the 'end point' of ethical research, I feel it is important to attend to the potentialities and the hopeful futures for Tourettic people, which are situated within these aforementioned spaces of 'belonging'. The following sections of this chapter attend to this in a way that considers the value of approaching the workshop as site and as process, how this enables knowledge sharing, and the valuing of contrasting experiences in solidarity-enabling ways.

### **6.3.1 Reflections on space and workshop as site**

As a part of the research design, it was planned that follow-up interviews would take place after the workshop to make space for reflection on the workshop itself. When carrying out the analysis of data from both the zineing workshop and the interviews following on from them, what was of clear importance to the participants who were involved in the workshop was the zineing workshop as a space itself. All participants focused the experiences and thoughts shared with me around the site of the workshop, rather than the zine as a final product itself. Unanimously, participants had positive things to say about the zine itself, but where the most insightful information came was through the analysis of and reflection on the workshop space and process of 'making'

~~themselves themselves~~. Fond memories of humorous moments from the workshop were shared, which demonstrated the joyous hope that was fostered within the ~~space,~~ ~~and space and~~ will continue to linger and have effect.

~~In a follow up interview with Bella,~~ she stated:

*[The workshop space was] chaotic ... well it wasn't, but in my head it was [...] But that 's a good thing. I don ' t mean it in a negative way, because you know ... you know yourself, being around others ... we trigger each other. That creates chaos without even having anything to do [...] Nevertheless still it was fantastically enjoyable.*

- Bella, Interview 2

Here we can see Bella sharing her fond memories of the space of the workshop itself. A lot of work might describe Tourette Syndrome as seemingly chaotic and do so in an overall negative light, in suggesting that chaos is an inherently bad thing. However, participant accounts of the experiences had here suggest otherwise. TIC Hull's main hub ~~, as described in 7.2.1.,~~ can be a site of chaos where Tourettic people meet and trigger each other on a regular basis, children running around sensory rooms and people ticcing freely. For Bella, this chaos was not a bad thing, and it was just an inherent part of enjoying a space with other Tourettic people ~~;~~ ~~the inherent chaos here referring to the suggestibility of tics in Tourette Syndrome~~<sup>35</sup>. ~~In fact,~~ not only did Bella state that this chaos was enjoyable, but others referred to funny moments ~~that may have been deemed funny precisely~~ because ~~of that they were very chaotic~~ chaos. ~~Porkchop as a follow-up from the workshop and the creation of Tic Tic Boom!, he~~ light-heartedly asked me "Has anybody mentioned me jumping out of my skin yet in other interviews?" ~~(Porkchop, Interview 2)~~. The tics of some other people in attendance of the workshop were making Porkchop flinch very frequently, which everybody seemingly found to be funny, and instead of trying to suppress the tics, everybody continued with what they were doing, inclusive of ticcing. It seems that everybody embraced these chaotic bodily rhythms, not fighting for control but rather enjoying the moments they produced and the encounters they inspired.

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<sup>35</sup> This is to say that tics can be picked up by other Tourettic people, such as through echolalia (repeating vocalisations of others) of others' vocal tics – these tics might linger after the encounter has ended.

Similarly, Stacey described the pleasure sharing space with other participants: shared about how they enjoyed the workshop space itself, largely due to the people who were present:

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RESEARCHER: If someone was to ask you what you got out of doing the workshop, what would you say?

STACEY: [...] just like being around people that understand, I think... yeah  
RESEARCHER: Mm, so it was more about the people and the workshop rather than the zine itself for you, is that right?

STACEY: Yeah [...] you go to [support] group every month, but obviously we don't do anything like that.

- Stacey, Interview 2

#### Stacey, Interview 2

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Stacey here discusses how the the people who attended the workshop were an important part of what made the are what space or the atmosphere enjoyable. They also touched touched on how there was something about the space that did not feel like a regular support group despite being hosted in the exact same location, with people who, for the most part, regularly attend the physical session and who knew each other prior to the workshop taking place. If this space can be considered an assemblage of material and social aspects, then the familiarity means that certain chance (positive) encounters are somewhat expected amidst the chaos and around fellow Tourettic folks who *understand* and won't raise concern when a glue stick might be thrown across the room (Bri, Interview 2). There is evidently reflection here that there was *something* different about the workshop space than is usually provided by the support group space, despite the shared location and attendees. Other similarities in the comparisons made between the workshop space and regular TIC Hull monthly support group meetings include the comparison made by Bella, in saying that "being around others... we trigger each other" (Bella, Interview 2) and Bri's expression of frustration over the confusion between suggestibility and tics versus tics being assumed as contagious (Bri, Interview 1). There are evidently a lot of crossovers between the workshop and the regular support group space at TIC that people referred to as a positive environmentPorkchop, Figure x;

BellaBella, Interview, but it is important to inquire into what it was~~was~~ about the assemblage of the zineing workshop space that felt~~felt~~ so distinct for these participants.

In explaining urban assemblages, Shaw (2014: 88) writes “An assemblage is located both in the objects and practices that we can identify in the world, and in the realm of the potential, containing aspects which have not yet been realised”. The space, or atmosphere perhaps, felt comfortable not only in what was identifiably similar (i.e. venue, people) but also felt positively safe in the potentialities of chance encounters still to come within the space, to return to language used previously in this thesis. The ways in which space is assembled can be defined by encounters still to come, and in the expectation of familiarity and safety for these forthcoming encounters. Specifically, this could be seen in the anticipation of increased tics or specific triggers (the not yet realised, potential) and in the identifiable practices such as throwing glue sticks, conversations had, bodies sharing spaces, and so on. We see critical disability studies’ concerns over the *capacitating* the affective bodies that might occupy a space in relation to the use of wheelchairs and mobility aids (Goodley et al., 2021). This is to say how affective bodies can assist in the facilitation of somebody acting in a particular way. Some of these concerns can be seen in the data collected throughout this project, but once again here I am arguing for these interconnections and assemblages as having possibility for beneficial experiences and not only the removal of power from disabled bodies. There are positive potentials within disability, not despite disability. There are hopes and promising futures in disability, so to speak (Goodley, 2007). Regardless, in determining the distinguishing factors, we can look towards hopeful futures in which these hopeful spaces can be recreated and practiced moving forwards. Beyond this, considerations and suggestions might be made into thinking through the ways in which public spaces are assembled in ways that suggest either positive or negative chance encounters to come, as per the previous chapters’ discussions. In inquiring into this, we come to see that it is not only the way that the space was physically put together, but also how the space and its potentialities were remade and recontextualised through the zineing activity itself; the embodied practice of cutting, sticking, drawing, laughing, throwing, and so on offers some shifting [expected] potentialities for similar spaces, moving us towards futures that may be considered more hopeful surrounding Tourette Syndrome. The implications of this

remaking are in the expectations of future belonging, sense of community, and therefore hope that we discuss here.

Within the follow up interviews that took place after the workshop, a key difference of this space in comparison to support groups, both online and in person, was the presence of an activity *for* adults with Tourette Syndrome. As explored earlier in this thesis, and as Lorna stated in her interview, “once you hit 18 you kind of disappear off the face of the earth when it comes to services and support” (Lorna, Interview 1). ~~Evidently, this includes specific activities such as the zineing workshop that was facilitated as a part of this research.~~

~~It has been explored how~~ Some participants were concerned about being overwhelmed with in person support groups ~~too~~, and Pete raised a valuable point to follow on from the workshop:

*In a way, by focusing on what I was writing it could distract from that. So in a way it was my little escape. I don't know if you noticed, but mine were all writing tasks and I did that so I could get lost in it a little bit more, which tends to be something I do when I am really bad [and ticcy]*

- Pete, Interview 2

~~Alongside this,~~ Stacey also mentioned that the fact there was an ‘activity’ for adults to engage in is what stuck out to them ~~them~~ as something that they enjoyed (Stacey, Interview 2). This is in comparison to a lack of activities catering to Tourettic adults in support groups elsewhere. Having these kinds of activities for Tourettic adults could be considered as an act of solidarity in a landscape where people with TS ‘*disappear off the face of the earth*’ once reaching the age of 18. Solidarity has been referred to in terms of collaboration (Ritchie & Rigano, 2007), caring and supporting one another (Jennings, 2018), and has even been explored as demonstratable through artful practices from street art and graffiti (Christensen & Thor, 2017), to theatre-making (Pufahl *et al.*, 2021; Warren, 1998) to zineing (Schilt, 2003; Smith, 2012). However, perhaps the very act of having an artful *activity*, specifically, is also to be considered active solidarity? ~~The~~ The purposeful allowance/affordance of socio-material interactions - be it in the echopraxia of slapping a table in response to somebody dropping their phone onto it or the cutting, sticking, tearing of papers in response to conversation and recalled emotional encounters in

public spaces – is active solidarity. But perhaps most simply, solidarity is expressed here through the fact that there was a space focused on Tourette adults.

It is interesting here to note that through focussing on space/site of the workshop, we can come to realise similarities between the above reflections of the workshop and draw comparisons to participant accounts of physical public spaces. For example, Pete shared his experience of how he most comfortably navigates and uses supermarkets with me in an interview:

*If I go [to the supermarket], it's not as bad 'cos I know where I'm going and I know what I'm doing, so if I get pissed off I'll just leave. I go with [my partner] and she's like "Oh, let's go to aisle 3, then aisle 1, then aisle 5" and I don't know what the hell she's doing. So I'll be following her and she'll randomly stop and start looking I'm like "What the hell are you doing? You said we came in for this and we're not there"*

- Pete, Interview 1

This is one example of the way that some participants' experiences seemed mirrored between both physical public spaces and the zineing workshop—specifically. Pete expresses the uncomfortability that he experiences when going to the supermarket with his partner. He takes the approach of careful planning and of using the space of the supermarket in a set way, where he has a specific goal or activity to do. In contrast, his partner takes a more spontaneous approach that he feels less comfortable with. Comparisons here could be drawn between a preference for engaging in a set activity with a previously planned structure rather than a more spontaneous approach when comparing Pete's account here of public places with zine workshop attendees' accounts of enjoying the workshop specifically due to the activity being a part of it. With service provision being limited for adults, not only for Tourette Syndrome but across disabilities as a whole (cf. BBC News, 2023; Cvejic & Trollor, 2018; Glasby *et al.*, 2021; Mencap, 2020; Soltani *et al.*, 2019), this also means that it is much less common for support groups that cater for adults to hold regular activities in the same way that they might do for children and young people. The facilitated activity, notably the practice of collaborative zineing, allowed for the sharing of solidarities in and around creative work. The material act of cutting and sticking, the exchanging of stories and experiences, and the development of Tourette knowledges were enabled through a focus on *doing* rather than the making of an end-product within the workshop space, as the following sections will attend to.

Where charities, services, and support generally might exist (albeit rarely of satisfactory quality based on participant accounts), what seems to be missing from these already limited spaces is *activity* provision. General interview conversations throughout the project seemed to bring to light that *something* was lacking from support group spaces beyond microaggressions experienced from non-Tourettic stakeholders in Tourette Syndrome. However, with considerations surrounding ~~the lacking of~~ activity-spaces here we can begin to make some further connections in accounts of support group spaces (and otherwise). Pete shared in a follow-up interview that he was engaged in a non-TS specific creative writing club (Pete, Interview 2) whereas when previously asked about support groups and the kinds of things he *does* in the context of discussion surrounding a support group, he didn't mention this (Pete, Interview 1). ~~It~~—there was an automatic assumption that this was not relevant by him, suggesting that activities such as this and support groups are perhaps two completely separate things. Furthermore, Tabitha spoke about how an international-scale Tourette Syndrome exchange programme was the first time many had been able to engage in activities (due to concerns about safety by even TS charities organising support groups) (Tabitha, Interview 1). ~~Even as far back into~~ ~~In the project's~~ ~~the project as the very~~ initial advisory focus group, ~~there were~~ conversations about actively *doing* things that require focus to help minimise tics were had, be it in Danny's love for the cinema, or in Ace talking about not necessarily enjoying the space of a club but rather engaging in the *rave* through dancing (Advisory Focus Group 1). Whilst still limited, there are significantly more activity-centred services that do exist within the wider landscape of disability for adults nationwide. Just two significant examples of this can be seen in *DanceSyndrome* – a Lancashire-based dance programme for people with learning disabilities<sup>36</sup> – or *Twisting Ducks*, who run workshops, produce theatre by learning disabled people, and have weekly sessions for disabled people to engage in creative activities such as DJing and acting (DanceSyndrome, 2023; Twisting Ducks, 2023). ~~Work with Tourettic adults would benefit from thinking through difference activities, like the aforementioned example organisations have done, and this is~~

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<sup>36</sup> Though it is important to acknowledge that their *goal* is not specifically to focus on learning disabled people but rather to be more widely inclusive.

~~something that I aimed to experiment with in the workshop space as a means of enhancing and facilitating solidarities.~~

From my own experiences adult TS support tends to centre around getting a hot beverage and catching up with each other somewhat awkwardly whilst Tourettic children *do* activities. Alternatively, the adult-based ‘activities’ centre around a significant evening out, such as going to a pub; playing bingo, or going to the theatre, to use some examples of activities that TIC-Hull has facilitated previously. The adult activities seem to focus on being ‘out and about’, engaging with the very same public spaces that oftentimes people are wary or anxious of. The stresses of public spaces such as parks, shopping malls, pubs, theatres, and so on have been discussed at length in previous chapters. Although these ‘trips’ might be designed to help people access the spaces they feel excluded from, the underlying uncomfotability of those places means that the potential for sharing solidarities in the matter of sharing stories and knowledges, is hindered. TIC-Hull arranges semi-regular activities with the limited adult-service funds they receive for adults with Tourette Syndrome, of which many participants from this project have attended previously. However, it appears that the activities in question that people feel are missing here are ones such as this zineing workshop; artful activities that are less public, and happen in what feels to be a safer space. Activities in spaces that feel a little safer, such as TIC-Hull’s main hub as explored by Porkchop (see *Figure 7*), such as process-based arts workshops are perceived as valuable by those who engaged in the zineing workshop. It is in these spaces, and through activities such as zineing, that can enable the sharing of complex solidarities for Tourettic people, with people feeling less of a need to suppress tics and feeling more able to ~~be visible~~ be visible in their Tourettic symptomologies. Those involved in the zineing workshop felt listened to, and able to share freely. Yebby shared that she felt that “everyone was so understanding and nice [...] I definitely felt like [I] belonged in that space” (Yebby, Interview 2). Bella even shared that she felt able to open up because “You’re looking at completely different diverse backgrounds, and I feel included by that. It feels validating. I don’t just have to be Bella with Tourette’s, I can be Bella who’s transgender and who’s got different experiences to someone who’s cis or straight or whatever” (Bella, Interview 2). The space felt inclusive for folks and this allowed more comfort in opening up about experiences. Despite some activities in public spaces being available for them to engage in, the ability to share these

complex solidarities in a safer space through the activity, or the *doing* of zineing here is key.

Part of the complex solidarities that zineing methods allow (cf. Schilt, 2003; Smith, 2012) include not only the acknowledgement of contrasting experiences, but more specifically the *valuing* of these experiences too. Looking back on River's accounts of internationally leading Tourette Syndrome charities actively excluding people without a specific experience or manifestation of tics in a way that is not deemed 'palatable' (River, Interview 1) we can see that these more public-facing activities are also not designed with the diversity of the Tourettic experience in mind. Tourettic adults **as a whole are** not the focus of these spaces of activity. When people are not safe to express and share their authentic experiences, whether in the violent act of being removed from a Tourette Syndrome residential event or otherwise, this is a failing of these spaces and does not allow for the sharing of solidarities. Having activities to engage in, whether more privately such as in the workshop space or more publicly such as activities available at aforementioned TS residential camps, is key in fostering safe spaces for these solidarities to

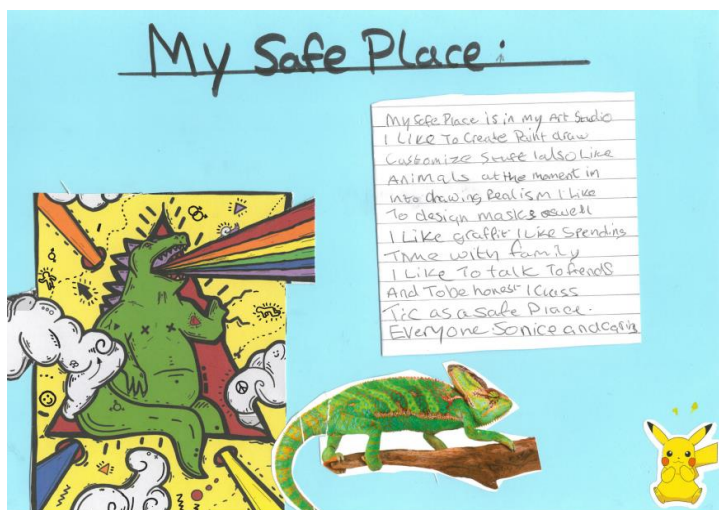


Figure 7: A collage created by Porkchop exploring what 'a safe place' means to him. The text reads: 'My safe place is in my art studio. I like to create, paint, draw, customize stuff. I also like animals at the moment I'm into drawing realism. I like to design masks as well. I like graffiti. I like spending time with family. I like to talk to friends and to be honest I class TIC as a safe place. Everyone. Sonice and caphy'.

blossom. The process appears rather circular. With the blossoming of these solidarities, hope for a more inclusive, safer future full of solidarity and positive possibilities for encounters also come to fruition. Chapter 5 particularly focused on ideas surrounding

loneliness. It is through the formation and facilitation of these solidarities that a cycle of sorts begins, this process is circular and works to strengthen solidarities, belonging, and so on not so dissimilar from the proposed Tourette Syndrome cycle of inadequate support and misunderstanding shown in Chapter 5. Where the failures of many support services result in some still not feeling a sense of belonging, a shifting focus towards solidarity sharing might offer this. A solidarity focused approach might work to reduce loneliness and isolation through acknowledging the diversity of Tourettic experiences. This offers us some hope for the future of Tourette Syndrome support services, but also goes beyond this in allowing us to think through what public space, more generally speaking, *could* look like. If there are problematic cycles of strengthened unbelonging, what is to say that there cannot be cycles of strengthened solidarity and belonging in a similar manner? Considering process and space here allows us to consider ideas for a hopeful future where Tourettic adults feel as if we belong in these support spaces.

### **6.3.2 The zineing process as allowing and valuing conflicting experiences**

Smigles (2023: 31) explains how “being disabled or claiming a disability identity says very little about a person’s experience of ableism” and this was very much evidenced within the interviews and focus groups carried out throughout the course of this research project. These conflicting and varied accounts and experiences were expected when beginning this research, and there was evidence of this throughout interviews, focus groups, and the zineing workshop. These contrasting experiences and/or opinions might be held back or felt to be invalid precisely due to their contrasting nature, but existing spaces for discussion appear to present a one-size-fits-all approach to describing Tourettic experiences. As previously explored, this might be in the descriptive example of a tic feeling like a sneeze, or in spaces where repeated reference to children with TS are mentioned to suggest that Tourettic experiences are not adult ones. To use just one example of many, in a focus group with members of TIC-Hull, the following interaction occurred:

***PETE:** I think I’m always in the way. I think if I’m in the way, I need to be out of the way. I don’t know if it’s being a tall thing because you’re always a big person in the way, so when you’re, say... it’s like you go into GAME and you’re looking through the games and someone’s in your way and you’re like “nope” like, you look first and I’ll just wait ‘til it’s empty.*

**RESEARCHER:** Yeah. So do people feel similarly or different? Maybe STACEY or PORKCHOP maybe? Do you have a similar thing?

**PORKCHOP:** Mmhmm. I hate small places.

**RESEARCHER:** Sure. How about you STACEY, how do you feel about all that?

**STACEY:** I don't know, I'm quite alright really. It's just... I get... like paranoid about people staring at me, but other than that I'm quite alright.

- Advisory Focus Group 2

Here we can see [thatthatPete Pete](#) and Porkchop refer to feeling like they are 'big' and 'in the way' as such, in feeling that they might be subject to disableist responses for being in the way of people who happen to be positioned behind them. However, Stacey replies and says that they are 'quite alright really', suggesting that whilst they understand Pete and Porkchop's dislike of feeling that they are in the way and that they are being watched, Stacey does not necessarily dislike these spaces or even the scenario that Pete described. However, in Stacey starting their [responsewithresponse with](#) 'I don't know' suggests to me that they may have been holding back. In an interview with them, we had the following conversation:

**STACEY:** Um... I don't really know, 'cos I like open spaces but then I like spaces that are noisy, so like people don't hear me.

**RESEARCHER:** Oh, okay! So like open but busy too?

**STACEY:** Yeah, so... yeah so I'm not claustrophobic.

- Stacey, Interview 1

Here, Stacey elaborated on the aforementioned dialogue occurring in the focus group with Pete and Porkchop. Stacey held back and did not elaborate in the context of the focus group, and this is evidence of not necessarily feeling able to share conflicting views in the focus group space. It wasn't that small spaces do not really have a negative impact on Stacey, as they might do with Pete and Porkchop. Specifically, it is that Stacey's experiences are a little more complex in that they do not like spaces that are too small due to feelings of claustrophobia, but also that noisy spaces are usually smaller spaces, and it is these noisier spaces that they prefer. Meanwhile, conflicting experiences of the types of spaces people felt most comfortable in differed. Some people preferred loud spaces and spaces of intoxication whereby tics may go unnoticed

despite heightened tics (Stacey, Interview 1; Ace, Advisory Focus Group 1). Others

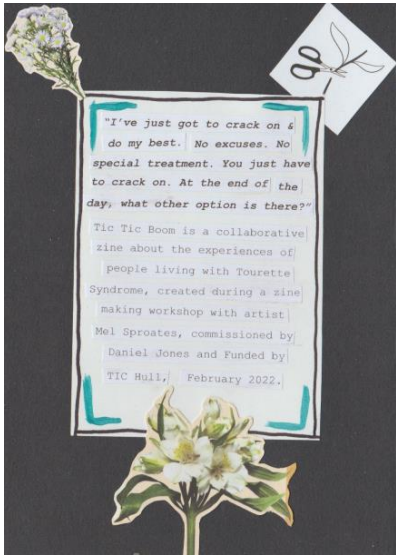


Figure x: The back cover page of collaborative zine 'Tic Tic Boom!', featuring a quotation from a creative writing response by Pete.

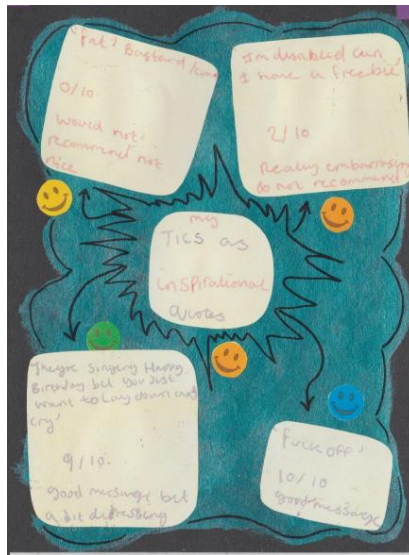


Figure x: A page from the collaboration zine 'Tic Tic Boom!', featuring extracts from Stacey's mini-zine 'My tics as inspirational quotes'.

expressed significant dislike of these loud spaces of intoxication due to it triggering their tics (Lizzie, Interview 1). Other instances were clearly visible in the artwork of zines.

One contribution that stood out to me was Pete’s work, which can be seen on the back cover of *Tic Tic Boom!* (shown in *Figure 8*). Pete engaged in a lot more written responses than visual as he particularly enjoys creative writing (Pete, Interview 2), and this resulted in some particularly interesting written responses that are quite distinct. Specifically, the contribution that stuck out to me is, once again, “I’ve just got to crack on & do my best. No excuses. No special treatment. You just have to crack on. At the end of the day, what other option is there? What other option is there?” For me, I

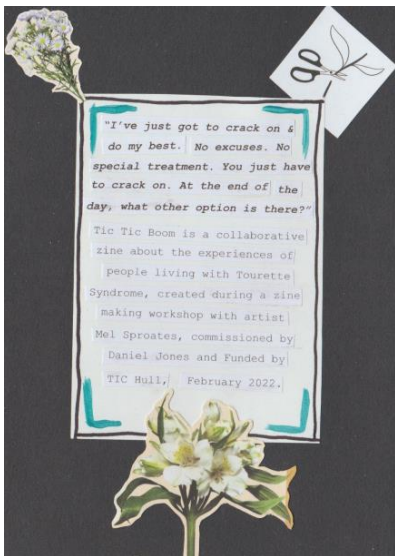


Figure 8: [The back cover page of collaborative zine 'Tic Tic Boom'](#), featuring a quotation from a creative writing response by Pete.

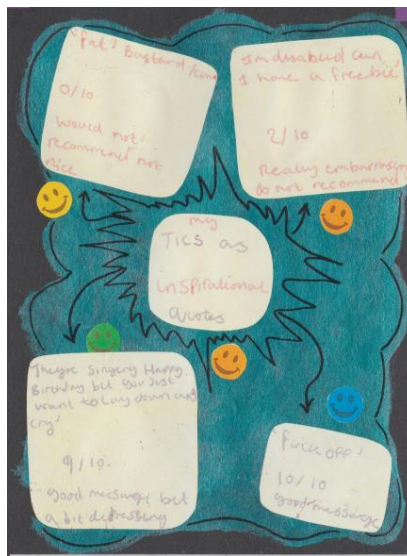


Figure 9: [A page from the collaboration zine 'Tic Tic Boom'](#), featuring extracts from Stacey's mini-zine 'My tics as inspirational quotes'.

instantly thought

about the value of access to work adjustments; the way that disability benefits had been instrumental in helping with my own access needs; and even the ways that I had been welcomed when searching for Touretic community and sense of belonging myself. I felt uneasy at first with this. There were contrasting experiences and opinions expressed within the zine and the zineing workshop too, such as in Stacey’s creation of a mini-zine titled ‘My tics as inspirational quotes’, of which was incorporated into the final zine (*Figure 9*). Specifically, one section reads: “Fuck off 10/10 Good message”. In comparison to this, we see that when creating work about coprolalia, specifically cuss words, Bella drew a stick figure with a sad face, surrounded by words

such as 'cunt', 'fuck', 'shit' and 'wanker' which she has experienced as tics before. Evidently, Bella does not refer to coprolalia in a similar light, and this frustration was also expressed in an interview with Bella, whereby she shared about the frustrations and stresses she experiences in her life as a result of coprolalia. To draw once more upon this insightful interview extract:

*there was a lovely lady in a- well she might have been lovely, she might have been a twat I don't know- in a hijab. But then of course I'm there thinking "Suppress suppress suppress suppress!" 'cos it was going to be "ISIS" or something bad. I pushed myself away, and get round the corner and what do I see next? Another woman in a hijab. And I was like oh for fu- will life give me a break? Will life let me be nice to people and respect people?*

- Bella, Interview 2

Evidently, there are various instances from all aspects of the data that highlight the varied and conflicting embodied experiences of public space and Tourette Syndrome that are had by people, additional to those that significantly contrast against my own embodied experiences as a Touretic researcher myself. These contrasting experiences were discussed within the zineing workshop, and in collaboration with one another the contrasting experiences were still agreed to be included within the final zine by everybody. This was regardless of whether or not they could relate to the experiences shared by others. By now it will be abundantly clear that people's experiences of Tourette Syndrome are significantly varied not only in the manifestation of symptoms but also in individual embodied experiences of them. However, what is key to consider here is how the zineing workshop allowed for the validation of these contrasting experiences in a solidarity-ensuring way that felt safer to share knowingly conflicting experiences with people in the way that Stacey felt they could not in the context of the focus group.

The importance of these contrasting experiences being shared, and of the safe, welcoming space of belonging being facilitated to allow the valuing of these contrasting experiences, cannot be emphasised enough and goes beyond the fact of it being valuable for this research. In a landscape where fake-claiming is rife on social media sites,<sup>7</sup> popular media documentaries,<sup>7</sup> and peer-reviewed academic publications, people do not always feel that they can share their authentic experiences of Tourette Syndrome. For example, in this research multiple participants shared their experiences of not feeling Touretic-enough or that they presented as being Touretic in the *wrong* way (as in did not have

coprolalia as one of their TS symptoms) as a reason for not wanting to post on social media about their experiences. Participants also shared experiences where they'd been accused of faking themselves, both in online and physical spaces. The ways in which people were comfortable sharing these conflicting experiences within the scope of the workshop space highlights the possibility for alternate realities (individual experiences) to occupy the same space without conflict arising. The experiences shared might have been contrasting, but they cannot be described as conflicting when the space in which they are shared allows all people to be equally present in sharing their stories and experiences. With participant experiences of both physical and digital public spaces being littered with the chance encounters of conflict, even internally within the Tourettic community and between Tourettic people, spaces like these are incredibly fundamental for ensuring future sense of belonging. Creative arts spaces that are focused on process, such as the workshop held within this research project, are fundamentally full of potential to act as the facilitators of solidarity sharing and therefore also of hopeful futures of belonging.

### **6.3.3 Knowledge sharing: language and ability to vocalise Tourettic experience(s)**

Within the zineing workshop, whilst valuing contrasting experiences was key in ensuring the sense of belonging of participants within the workshop space, the sharing of Tourettic knowledges was also key. Looking back to some considerations of previous chapters once more, there were some instances of participants not being fully aware of what Tourette Syndrome encompasses, despite their diagnosis. For example, when asked about her tics, Madge (who was not a participant of the workshop) stated that she was not annoyed by her tics, but more so by her vocal outbursts (Madge, Interview 1). What Madge meant by this, was that the motor tics were not as frustrating for her as the vocal tics she experiences. However, Madge was not aware that vocal tics were a symptom of Tourette Syndrome and required for diagnosis; Madge was unaware that her 'vocal outbursts' were in fact tics and were a vital factor in receiving a diagnosis of Tourette Syndrome. Further to this, there is a huge variation in the language being used to discuss Tourette Syndrome, particularly in online spaces but even amongst medical professionals and published research as explored earlier in the thesis. Once more, the question is raised about how we can expect Tourettic people to have full understandings of Tourette Syndrome when medical professionals themselves are also publishing confused and conflicting research

about it. This significant variation in the ways that participants understood their own Tourettic bodies and experiences means that some might refer to themselves as disabled, some may identify as neurodivergent (and some as both or even as neither) in relation to their Tourette Syndrome diagnosis. Some may not have had an opportunity to discuss this previously, or perhaps might not have had the language to explain their own experiences, and so the arguing that happens in some spaces even between community members about what constitutes Tourette Syndrome is key to consider. This causes further divide and isolation amongst the Tourettic community, and highlights the need for spaces like the workshop whereby a sharing of languages can occur, and people are able to make



Figure 10: A mini zine created by Pete, featured in 'Tic Tic Boom!' made in response to the prompt 'What would you like to tell the world about what it's like to be you?' (Pete, Tic Tic Boom!)

sense of their own Tourettic experiences. With confusions over medical language and diagnostic criteria, considering non-medical identity through understanding the self is vital, and the workshop appeared to provide this for those involved.

Shared identity and sense of community was fostered through the stepping outside of the confines of medical identity and in some instances text or spoken word that occurred within the workshop. Through people sharing experiences that others could relate to, using language that made sense to them, other people in the workshop were able to make sense of their own experiences. It is partly for these reasons that the

workshop was powerful as a way to share Tourettic knowledges of Tourette Syndrome, and provide group hope for the future. One example of participants in the workshop being able to make sense of their own experiences through other people's words and expressions of their experiences of Tourette Syndrome was raised by Bri. In referring to a mini-zine created by Pete, Bri shared how the sharing of metaphors to describe tics was particularly important to her:

*[My favourite part of the workshop was] seeing everyone else's mini-zines, especially Pete's with the... was it a wasp or a bee or a fly or something that kept buzzing was it? [...] I just relate to it so much, and it was so simple. I couldn't have thought of that. It was so simple and such.... it demonstrates such a good point about how annoying it is, and how overwhelming it can be.*

- Bri, Interview 2

Here we can see that Bri is very grateful for Pete having shared his experiences in the form of his mini-zine (Figure 10). Through communicating his experiences without even the need for words, Bri has come to relate to his experiences and in some way has been given a new language or metaphor that is simple enough to adopt when trying to explain Tourette Syndrome to other people. This is of particular importance for Bri especially, given that in an interview she discussed how it was comforting to have people do the thinking-work of explaining Tourette Syndrome and tics to other people within public spaces (Bri, Interview 1, Interview 2). Having this (now) shared language to apply when navigating the politics of disclosure in public spaces allows for Bri to feel perhaps more connected to the Tourettic community. In a way, this shared language can help to combat the sense of loneliness that is experienced amongst Tourettic adults. This left me wondering how Madge, who asked "who would even care?" might feel if ~~perhaps~~ she perhaps was able to share her experiences of adulthood onset TS with others in a space much like the zineing workshop. The embodied practice involved in the zineing workshop - sharing stories, cutting paper, sticking images, and so on - work to combat loneliness in a way that lingers beyond the workshop itself, through the sharing of languages to discuss and disclose Tourettic experience(s).

#### **6.3.4 Comparisons to TS only spaces, and the value of performing body-absence**

Throughout the project, notions of what *private* and what *public* meant regarding questions about public space were key in their discussion; on the whole, participants discussed *public* space to mean spaces that were primarily those in which there were

people who did not have a diagnosis of Tourette Syndrome, with suggestions that TS-only spaces, or publics, were to be considered private. This privacy, however, was not simply an absence of people, but rather an absence of non-Tourettics. Spaces exclusively for Tourettic publics were, on the whole, conceptualised by participants as *private* space. With the comparisons previously made between the workshop and the support group spaces, it's also interesting to explore the comparisons being made between Tourette Syndrome-only spaces and the workshop space in more depth. In previous accounts, particularly of online TS only spaces, comments were made about the incredible importance of these spaces being private and protected from non-Tourettic stakeholders in Tourette Syndrome, such as parents, carers, siblings, and so on. Frustrations were commonly expressed about parents asking inappropriate questions and complaining about their Tourettic children (Bri, Interview 2) or of making the Tourettic people in those spaces out to be a 'charity case' (Sugar Tits, Interview 1). It appeared that throughout the participant accounts of these shared spaces, with frustration as the overarching emotion being felt. What is interesting to note here is that the workshop space was also a shared space of sorts, as there were non-Tourettic people in the room too. This section addresses the participant accounts of their overwhelmingly positive experiences of the zineing workshop, and highlights what about that space in particular was distinct in its ability to enact solidarity.

Interestingly, one attendee of the workshop who wishes to remain unnamed here for privacy reasons shared:

*Sometimes at TIC I don't feel comfortable [due to certain comments being made by non-Tourettic people]. It's a shame when it's someone who hasn't got Tourette's coming to a Tourette's meeting and making someone with Tourette's feel uncomfortable. That's weird. But for it to just be us with Tourette's, like [name redacted] there without [parents/guardian names] was just beautiful to get [to know] them*

- Redacted<sup>37</sup>, Interview 1

The participant expressed that they were happy to have this extract shared, but did not want it to be written about in line with their pseudonym as they felt that the combination

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<sup>37</sup> The participant did not want to have their chosen pseudonym referenced here, and stated that they wished for some additional steps to be taken to provide anonymity here to allow them to still continue accessing the services that TIC-Hull without any risk of being treated 'differently'.

of the two may lead to unwanted identification. Here, the participant in question states that they enjoyed the workshop in part due to the fact that it was “Just [...] us with Tourette’s”, and the opportunities for building community that this facilitated. However, the workshop space did *not* ~~consisting~~ consist of ~~ing~~ only Tourettic adults. Also present were Zeke (the zine artist) and Bri’s carer and partner, neither of whom are diagnosed with Tourette Syndrome. How then does this workshop space feel similar to a Tourette-only space?

One key area of literature to acknowledge here is García-Santesmases *et al.* (2022) work on performing body-absence and body-presence. The paper explores bodywork in relation to personal assistants (PA) of disabled people, and of particular note is the value of performing body-absence. The authors refer to PA’s bodies as tools in their employers’ hands: “Body-tool is a key body performance in enacting the employer as the agent in command: PAs withdraw from taking part in situations despite being physically present” (García-Santesmases *et al.*, 2022: 9). This is also done in other instances such as assisting with hygiene. In some instances, “performing body-absence is a way of safeguarding the employer’s intimacy and comfort” (p10).

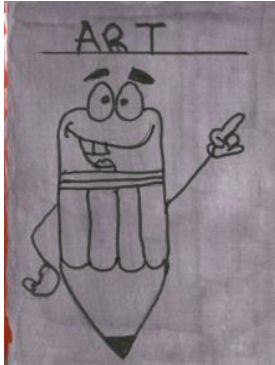


Figure 11a: Title page of a mini-zine by 'Porkchop'.

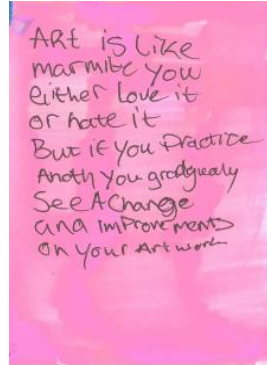


Figure 11b: Extract from Porkchop's mini-zine. The text reads: "Art is like marmite you either love it or hate it. But if you practices [enough] you [gradually] see a change and improvements on your art work

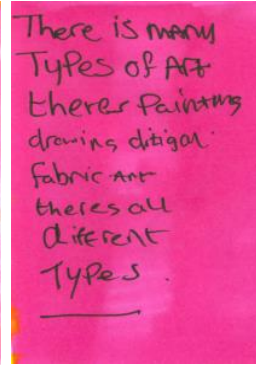


Figure 11c: Extract from Porkchop's mini-zine. The text reads: "There is many types of art. There's painting, drawing, digital, fabric and there's all different types"

A key element, in this paper, of giving disabled employers of PAs autonomy, comfort, and to some extent expressing solidarity is through performing this body-absence. I argue that Zeke, as zine workshop co-facilitator, and Bri's carer (or PA) both were engaging in the bodywork of performing body-absence during the session, and this is what results in the space feeling similar to 'Tourette-only' spaces previously discussed. For Bri's carer, this looked like engaging in the zine making activities without expectation to contribute to the collaborative zine, whilst listening and being quietly there to help if needed. Their acts here echo those discussed by García-Santesmases *et al.* (2022). However, I would also argue that Zeke, as facilitator, was also engaging in performing body-absence throughout the session. One example of this was through the act of explaining a task and then allowing people to engage with it as much or as little as they might like. For example, Porkchop created a 'mini-zine' titled 'Art' (Figures 11abc). Instead of speaking up and questioning the specific links between the prompt of 'safe space' and Porkchop's zine, Zeke did not speak up and question this. Zeke kept an eye to see when there might be a need for being more noticeably present in the space in needing assistance; they would share and explain the prompts and goals of the day, and then sit back and listen, performing body-absence, until help was needed. When following up with Porkchop after the workshop, the following dialogue occurred:

**PORKCHOP:** Like... that's one thing [redacted] knows about me. You remember that... I don't think you was there. They did that Tourette's night out at that pub, there were two kids in the toilets who were sat staring at me and I was like fucking- I was like "I'm going out". So I went out the toilet and I said to [redacted] "I've just had to come out" because, yeah... otherwise I'm gonna' end up filling them in<sup>38</sup> in that toilet. [...] Well when I was in the toilet [and] my face twitched and they was taking the piss out of that. I went mad.

**RESEARCHER:** Yeah. Thank you for sharing that with me. Do you find that happens much still? Like what sort of places did it tend to happen?

**PORKCHOP:** It can happen any time anywhere really, can't it? [But it didn't in the workshop]

**RESEARCHER:** In your experiences though, where was it?

**PORKCHOP:** Look, this is my art studio

**RESEARCHER:** Oh amazing!

**PORKCHOP:** Nearly done!

**RESEARCHER:** It looks great

- Porkchop, Interview 2

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<sup>38</sup> Here, 'filling them in' is local slang for physically attacking the people in question.

In this interview extract, Porkchop and I were discussing safe spaces and what they felt like or consisted of for him. He responded in a way that focussed on a space that did *not* feel safe by talking about a recent negative experience he had in a pub. He shared elsewhere that the main hub of activities for TIC was somewhere he felt safe in because of the people, and then referred back to art and his involvement in helping to paint a mural at the charity offices. Through repeatedly referring back to art spaces, whether the mural wall at TIC, or through showing me his home art studio through a Zoom call, he was referring to artful spaces as safe spaces for him. It is the safety and security in artful spaces that Porkchop feels that inspired his mini-zine entitled 'Art' and is the reason for the artwork that others shared they did not necessarily understand: "[I loved] how proud he was of that pencil. I don't know what relation it has, but it still makes me laugh" (Yebby, Interview 2). Zeke and I also discussed Porkchop's zine following the workshop, pondering its relevance. However

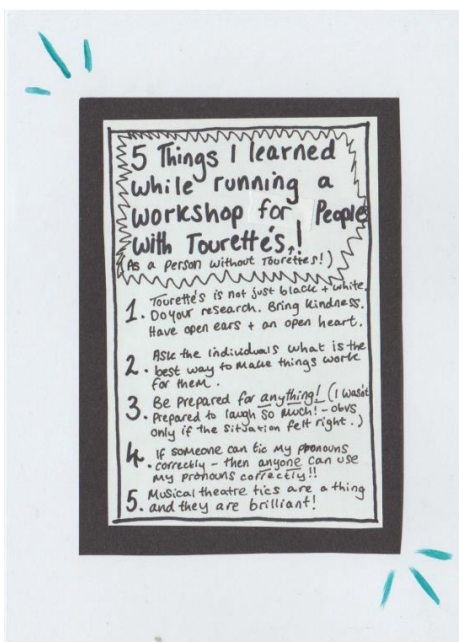


Figure x: An extract from 'Tic Tic Boom', consisting of Zeke's reflections about what they learnt about Tourette Syndrome during the zineing workshop.

despite having the goal of creating something consisting of people's responses to the workshop prompts in the form of a zine, Zeke performed body-absence through not policing the content or the ways in which participants responded to the prompts. Body-absence can be performed in many ways, some more explicit such as those outlined by García-Santesmases *et al.*'s (2022) discussion of personal assistants performing body-absence to allow privacy when their employers are showering. However it can also be as subtle as the examples mentioned here.

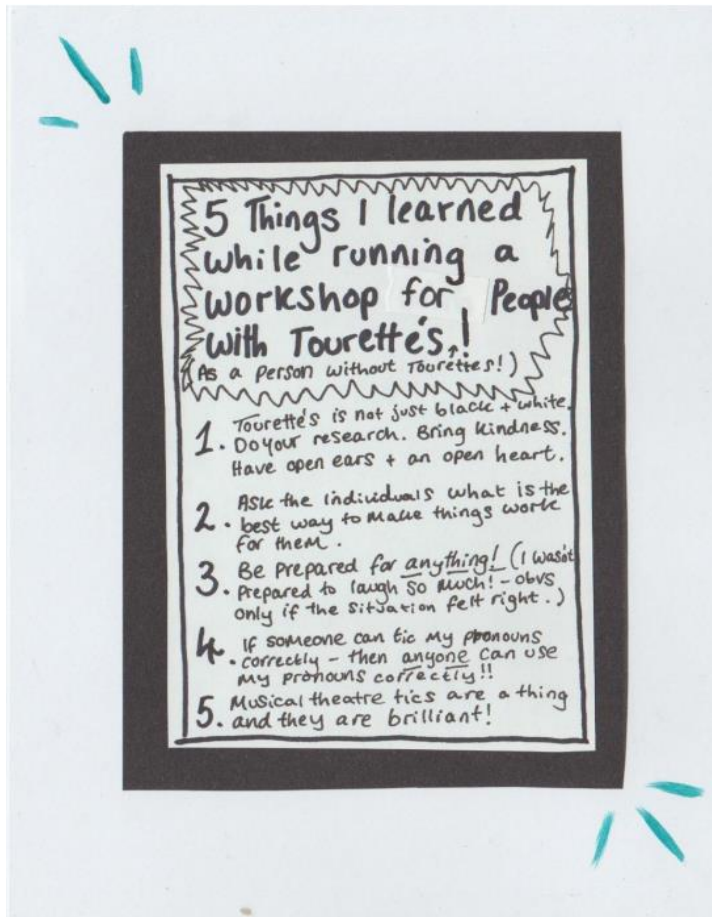


Figure 12: An extract from 'Tic Tic Boom', consisting of Zeke's reflections about what they learnt about Tourette Syndrome during the zineing workshop.

Another example that is important to mention is the fact that Zeke also engaged in the activities they were assisting in the facilitation of. The participants all invited Zeke to share their work. Upon sharing their creation about what they learnt about Tourette Syndrome during the session (Figure 12), the Tourette participants also invited Zeke to include this in the zine. This is significant to consider, and it highlights one of the key differences between participant accounts of support spaces, particularly those hosted digitally on platforms such as Facebook. Frustrations have been expressed about these spaces, from

Sugar Tits' concerns of parents making Tourettic children out to be 'charity cases' to Bri's aforementioned concerns surrounding parents complaining about how their children's tics are annoying to them. Participants in this research project largely feel that these spaces end up being mainly *for* non-Tourettic stakeholders in Tourette Syndrome such as parents, carers, siblings and partners of Tourettic people. In online spaces in particular, videos are regularly posted by non-Tourettic parents of their children ticcing, airing their frustrations and dismay over the whole situation and their loved one's diagnosis. This is incredibly frustrating for Tourettic people and is evidence of the lack of performing body-absence being done by so-called advocates and allies. The difference here is that Zeke was specifically *invited* to contribute by the Tourettic people within the space, whereas advice, frustrations, and woes are posted frequently and without consideration of the wants and needs for protected Tourettic spaces in many online support groups.

On the other hand, the term *body-presence* was used by García-Santesmases *et al.* (2022) to describe the personal assistant as an 'acting body' (p12) in sharing that some personal assistants of disabled adults were not comfortable waiting for instruction, and so attempted to be pro-active in that there is an emotional "expectation of empathy and intimacy with the employer" (p13) when conducting work, and that being *present* is a key part of their role in allowing employers to know that the personal assistant is there and ready to help whenever needed. In the case of Tourette Syndrome, body-presence might be performed by a friend disclosing somebody's diagnosis of TS on their behalf to an onlooker, or through posting (supposed) advice in online forums for treatment of tics. Body-presence may be important in some instances, but when not paired with suitable or adequate performance of body-absence, it works to alienates Tourettic people from the very spaces that are, on paper, designed *for* them. The workshop allows us to make these connections and come to understand the power of performing body-absence in making Tourettic spaces feel welcoming despite the presence of both Tourettic and non-Tourettic people.

Further, given the significant variability of Tourettic experiences, along with people who might have contrasting and contesting experiences or opinions regarding TS, body-absence was also being performed by the Tourettic research participants themselves. One method of performing body-absence from everyday public spaces that Tourettic people engage in might be the suppression of tics, as discussed in previous chapters.

However, these performances took on a different manifestation in the workshop space. One such way was through attempting to not react to certain tics. For example, there was one incident where Bella ticced and cut a small amount of her hair by accident. Performing body-absence in this instance took the form of being aware of the situation and *keeping an eye* on it – nobody in the room laughed without consideration; jumped up, shouting “Oh my goodness, are you okay?”, or anything of the like. After Bella laughed and brought attention to the situation through intentionally telling the group and laughing, this is when the group began laughing with her. These performances of body-absence amongst/between the Tourettic people in the room were ways of showing solidarity and kinship with one another.

It is this performance of body-absence that is what seems to be missing from these online support groups that Tourettic people find themselves sharing with non-Tourettics. In Tourettic-only spaces, people’s accounts of the negative aspect of these appear to mainly be the lack of support, training, and so on. To draw on River’s account once more:

*Having the Tourette’s support group that’s not monitored by anyone is really hard because there’s some really distressed people and like we don’t know how to support someone who is suicidal or something. Like, there are some people in some dark times. Currently someone is homeless and we can’t do anything about it, but also the charity, [redacted for anonymity], haven’t helped either.*

- River, Interview 1

River’s experience in particular highlights issues of *actual* absence from space, in that there is no support or assistance with facilitation whatsoever. In fact, in this instance the case was actually that the funding for the facilitation was withdrawn and the charity *abandoned* the group, to mirror the language used by River elsewhere in this interview, which left the Tourettic adults as support seekers themselves to facilitate without any training, finances, and so on. Perhaps in this instance, the non-Tourettic (organisational-level) performance of body-absence might look like ensuring the securing of funds to continue the running of groups such as the one River refers to here. Moving forward in this discussion, it is important here to acknowledge that there is a stark difference between performed body-absence and *actual* absence – the work done

to *perform* absence here is in itself an act of solidarity, whereas the *actual* absence can be seen as an abandonment in this case.

There are obvious concerns over the body-presence heavy experiences had of non-Tourettic people in these spaces such as through parents complaining about children (Sugar Tits, Interview 1) or generally seeking support *loudly*. However, there are also concerns with the complete absence of (oftentimes) non-Tourettic support in the facilitation of these spaces (River, Interview 1). Through focussing here on the workshop space itself rather than the zine as a final product, we have come to be able to make direct comparisons between these kinds of spaces and highlight the value of, and need for, the bodywork of performing body-absence, not only by carers, but by those who stand in solidarity as non-Tourettic stakeholders in Tourette Syndrome. According to participant reflections, arts-based, process-focussed, spaces are great facilitators of this community building. These hopeful futures, then, are not exclusive to Tourette-only spaces; the sense-of-belonging transcends these private-public boundaries.

#### **6.4 Beyond hopeful zineing spaces**

Further to considerations of the zine as an artefact of the hopeful space of the zineing workshop, concerns over the supposed spreading of Tourette Syndrome were discussed (cf. Forsyth, 2021; Hull & Parnes, 2021; Olvera *et al.*, 2021; Zea Vera *et al.*, 2022). What seems to be the authors' actual concerns are over the suggestibility of tics and how Tourettic people can pick tics up, but these concerns have been widely discussed in recent years. In fact, the large majority of recent discourse surrounding Tourette Syndrome is focused on the tic as scary and as something needed to be limited in its so-called spread. However, the workshop space provided opportunity for care-free ticing and the sharing of tics in a way that felt far more hopeful than it did scary. People picked up tics. In fact, I picked up more coprolalia than I'd ever had before and it lingered with me for a long while, infiltrating every aspect of my life, outside of the context of this research project. Much like how the zine felt like an artefact of a space where belonging and hope for the future was central, these tics were similar. Focusing on process, rather than product, in this way allows us to understand the zine as an artefact of hope. In turn, this gives way for the understanding of tics, in this instance, as artefacts of hope also, despite how frustrating they might be in their lingering. I was endlessly frustrated as I attempted to suppress tics that used words such as 'nonce' and 'shit' whilst teaching my

undergraduate classes – a thing that hadn't been something I'd even had to consider beforehand. Students knew about my diagnosis prior to this but were not aware of my coprolalia specifically. However, along with every urge came the reminder that I belonged somewhere, not just in that workshop space but more generally within some kind of community. As per Chapter 4's discussions, bodies can carry affective atmospheres. The previous chapter acknowledged this in terms of negative impacts on future encounters within a space, but here we move towards the positive potential of said lingering. Hopeful futures may consist of people losing their voices or feeling achey and bruised from any lingering tics, but they are overwhelmingly spaces of Tourettic belonging. In the same way the zine left me with fond memories, to some extent the tics that lingered in my Tourettic symptomology did the same.

Focussing on process in this way, it allows us to see exactly how the space of zineing workshops and other process-focused artful spaces can foster a hope for the future. These spaces could be incredibly powerful in helping to foster Tourettic sense of belonging. Previous chapters have been clear in highlighting the value of a sense-of-belonging as something to combat loneliness. Through focussing on process here, we have been able to uncover some form of hope for the future. A sense of belonging breeds, hope, and “[h]ope involves looking towards the future with a sense of positive expectation and intentionality” (Barut *et al.*, 2016: 178). The question now arises of what exactly is this expectation and intentionality in the context of this thesis?

## **Chapter 7. Conclusions**

Tourette Syndrome can offer a lot to the consideration of public spaces, embodied experiences, and geography as a whole. This thesis has demonstrated some of the intricacies and nuances of the embodied experiences of (and in) public spaces that are had by Tourettic adults. In doing so, the thesis seeks to give representation in academic

literature to these nuanced experiences. This chapter is the last of this thesis. Initially offering a summary of arguments made throughout the thesis and their links with the initial research questions, it moves into some blue sky thinking regarding what a *perfect* space might be for Tourettic adults, and whether it is even possible. From here, with this blue sky thinking and overall thesis arguments in mind, recommendations will be made both for disability research and service provision. The research goes beyond being useful solely in the case of Tourette Syndrome, and this will be elaborated on too. It will draw out some key arguments surrounding creative and participatory research methods and consider the research's value as a whole to the field of geography more broadly speaking. Returning then back to the case of Tourette Syndrome, the chapter will revisit my initial concerns and confusions surrounding the research of Tourette Syndrome that I had as far back as during the completion of my MA degree in 2018, in an attempt to try and address these. Finally, the chapter ends with some conclusive remarks, and steps forwards for the future.

### **7.1 Linking key arguments back to research questions**

This section offers an overview and summary of the key points and arguments made throughout the data chapters, attributing the key discussion points back to the initially proposed research questions:

1. How is the Tourettic experience of public space distinct, and to what extent is Tourette Syndrome a barrier to using public spaces?
2. To what extent does social difference influence the Tourettic experience of publics, physically and online?
3. How can zine-based methods be used productively in researching the Tourettic experience of public space?
4. What can geographical consideration of a Tourettic point of view contribute in regards to...
  - a. Charitable organisations and their practices?
  - b. Healthcare professionals and their practices?

In providing a short and succinct summary of the arguments presented in the thesis, it contextualises the remainder of the chapter in looking towards hopeful futures of Tourette Syndrome discourse, Human Geography, and disability studies.

*Chapter 4: Chance Encounters: The Social Dynamics of Impulse and its Cycles* focuses on the concept of the chance encounter and considers the social dynamics of the impulse that it argues is inherent to Tourette Syndrome and the ways in which it is experienced. Outlining the incredibly diverse experiences of Tourette Syndrome, the constant is in the creative strategizing that takes place in an attempt to manage and navigate chance encounters. The chapter refers to this as a cycle that is influenced by Tourettic impulsivity. It concludes that the distinctiveness of Tourettic embodied experiences in and around public spaces is in the assumed requirement to creatively interact with these encounters, which particularly aligns with Research Question 1 in acknowledging the distinct experiences of public space for tourettic adults. These interactions are influenced by affective bodies but also the ways in which public spaces are designed, and the requirements for this creative strategizing are partly created through the ways in which public space is not so open to difference or *otherness*. Not only this, but also that the ways in which additional labour is experienced as a result of this are distinct due to the inherent impulsivity associated with tourettic bodies. Whilst additional labour is common amongst all disabled people, the ways in which it manifests in the case of Tourette Syndrome is unique and also asks questions of the ways in which social difference influence these Tourettic experiences through the need for seeking out anonymity and the suppression of tics to avoid these instances of *othering*.

*Chapter 5: Tourette Syndrome, Public Space and the Importance of Community* extends the considerations of chance encounters discussed in *Chapter 4*, applying them to digital spaces. In doing so, it emphasises the ways that Tourettic people experience othering, loneliness, and isolation in a variety of ways, and highlights how experiences in physical public spaces have led to a digital shift in support and community building amongst the Tourettic community. The distinct experiences of loneliness and isolation had by tourettic adults (influenced by social difference and othering practices) in and around public spaces have contributed to the ways in which tourettic adults use digital public spaces and social media in particular. In this digital shift, uneven power dynamics have persisted, and the chapter explains the ways in which the management of chance encounters in digital spaces might be conceptualised as a form of curation. This could be in the intentional act of leaving a digital forum space, or otherwise. However, the chapter concludes by offering some hope and it highlights that the ways in which Tourettic folks

practice solidarity and community-building is distinct in the context of social media, digital shifts in support, and so on. These spaces of solidarity are more often than not found in digital spaces, as opposed to in physical public spaces (cf. Research Question 2).

With this in mind, *Chapter 6: Creative methodological contributions to hopeful futures of Touretic belonging* returns to some methodological reflections from the project that lead on from ideas surrounding sense of belonging. The chapter gives a detailed outline of the space in which the zineing workshop was conducted and covers the specifics of organising a research space/site that aligns with some of the ways in which the previous chapter outlines are distinct ways for Touretic community and solidarity building. It argues that existing work in creative geographies is particularly well situated within practices of solidarity, and that zines are an appropriate way to explore this in more depth. It explores the purposeful allowance of so-called disruptive actions, such as tics, and that the purposeful allowance of conflicting experiences to be shared is key in promoting and facilitating cross-identity solidarity(-ies) within the Touretic community. In doing so it highlights the ways in which solidarity can be found and enacted beyond the digital realm. It outlines how despite previous chapters' accounts of non-Touretic stakeholders in Tourette syndrome causing stress and upset within TS spaces, that solidarity, community and belonging *can* be fostered beyond TS-only spaces and that creative workshop-styled activity spaces for adults are powerful in this way. In the chapter's focus on the process of zineing – as opposed to *zine-making* – it suggests that these spaces should be explored more, and allow us to look forwards to the future with positive expectations, and a hope for Touretic futures. Of particular interest is the ways in which the findings presented in this chapter respond to the finding in Chapter 5 that spaces of solidarity are more often found in digital spaces, rather than physical ones. The chapter highlights how zine-based methods can be used in productive ways (see Research Question 3), not necessarily in terms of producing zines to raise awareness about Tourette Syndrome, but rather productive in the sense of creating community, sense of belonging, and solidarity in physical spaces.

With this in mind, this chapter – *Chapter 7 Conclusions* – shall build on this, seek to address Research Questions 4a and 4b in detail, and use the arguments from

throughout this thesis to look forwards regarding research implications, raise disciplinary questions, and provide concluding remarks.

## 7.2 Hopes for Tourettic space(s) and a conservationist ethics of disability

“What are our hopes for a Tourettic future?”. “What are our desires and demands for spaces in the future?” These are questions that I have found myself asking through the analysis of the rich data that the project’s participants shared with me so generously. These were also questions I had at the start of the project. In the advisory focus groups, I asked questions in focus groups of what an *ideal* public space might be for the participants. Some shared specific spaces they liked or disliked, elaborating on their hatred of fluorescent lighting in supermarkets, or their love of quieter spaces (though individual preferences often clashed with each other). However, what is of particular note here is Kacey’s humoured reaction to my question:

*It's a bit of a paradox really isn't it? A public space that you enjoy*

- Kacey, Advisory Focus Group 1

Kacey’s response here has led me to reflect a lot over the course of this project about whether any kind of *perfect* public space could ever exist. Whilst we might gage from the data and analysis in this project that a *better* public space for Tourettic people would consist of a better level of understanding about Tourette Syndrome by the general public, and general attempts to make people feel like they belong, and are not *sticking out*; an ideal public space could be argued to be one in which we as Tourettic people can blend into and experience the same felt-anonymous status as our non-Tourettic counterparts. However, achieving this feels like a hope for the distant future. In the context of chance encounters and the ways in which public space is made and re-made in a moment-by-moment basis by an undefinable number of affective bodies, how could we ever even begin to design a perfect *space*? Additionally, in the same focus group, Kacey also shared that the only consistent thing about Tourette Syndrome is the inconsistency, to which other participants all nodded and shared words of agreement. Whilst it might be nice to imagine one singular way to design public spaces - whether a supermarket, green space, or otherwise – the question is raised of how to respond to that. One space that might have been described as a safe space to some could be a space of particularly significant triggering for others. How can we begin to think about a perfect public space when even

my own internalised ableism leads me to think about the individualised experiences of public spaces? Space is never created, facilitated or negotiated in isolation. The collaborative nature of public spaces was particularly highlighted in the zineing workshop space, as explored in Chapter 6. There are common embodied experiences in Tourette Syndrome, whether in the creative strategizing and management of *chance encounters* or the general heightened experiences of loneliness and isolation. However, the things that other us in similar ways as Tourettic people can vary significantly. Whilst we might argue for scaling-up the ways in which the solidarity-facilitating zineing workshop space was arranged, perhaps these *kinds* of spaces are more valuable at a smaller scale. How accessible and inclusive might a zineing workshop with 100 participants felt in comparison to that hosted with 6 attendees? I would argue that it would be counter-intuitive to try and scale these kinds of spaces up. Designing all public spaces to consider individualised care plans, content warnings for every person encountering the space, etc is not necessarily possible. The raising of general awareness of Tourette Syndrome and the experiences that adults have, along with the correcting of stigmatising Tourette Syndrome research, might have a generally positive impact on making Tourettic adults feel a greater sense of belonging in public spaces. Beyond this, however, perhaps it is not so practical to scale up what was created in the zineing workshops. In this regard, if we consider what Tourettic space might look like, rather than thinking of the *perfect* public space more generally, blue sky-styled thinking might lead us to ask much more significant questions that perhaps feel a little more abstract at first. How can we *conserve* and allow sense of belonging for Tourettic people when it comes to public spaces?

During the closing conference for ERC-funded project *NeuroEpigenEthics*, renowned disability and bioethics scholar Rosmarie Garland-Thomson delivered a keynote in which she made a case for what she termed a 'conservationist ethics of disability'. In short, this entails the following:

- 1) A conservationist ethics focuses on creating a supporting material context, a moral ecosystem, in which human embodied experience can successfully thrive as it is.

- 2) A conservationist ethics aims to strengthen the cultural, political, and institutional climate in which disabled people most effectively flourish.

First and foremost, it is important to acknowledge that Garland-Thompson's presentation concluded with a call for this *kind* of ethics of disability, and that it was an idea that needed working through in order to figure out the exact features of conservationist ethics that could do what she wanted it to. Taking this starting-point of conservationist ethics of disability would help to move us closer to this idea of *perfection* and aid us in the blue-sky thinking activity of imagining Tourettic spaces in the future. Rather than considering the ways that we can imagine *perfect* spaces as a distant future, the approach of considering a broader moral ecosystem whereby disabled people can flourish allows us to think about the specifics and to offer *next steps*, as such, to making our blue sky thinking feel less of a distant future, and more imminent. This is not to necessarily advocate for a universal design approach to public spaces, but rather to acknowledge that the creation of these *Tourettic spaces* such as that in the zineing workshop are useful in helping Tourettic adults to feel that they belong *somewhere*. Universal design offers a lack of clarity and takes a very much one-size-fits-all approach to the design of public spaces (Aflatoony & Kolaric, 2022; Knudson, 2018). If anything, this thesis has shown the incredible variety of adult Tourettic experiences. Instead of questions about how to universally design spaces to be accessible for all in these ways, questions should instead be asked of 'how can we preserve disabled cultures, livelihoods, etc?' By taking this approach, we ensure that we do not seek to remove elements of Tourettic lifecourse, but rather *allow* for them. As the zineing workshop demonstrated, in the allowance of tics and other tourettic disruption, solidarity was created. Tourettic people need to be centred in order to allow flourishing, solidarity, belonging, joy, and so on. This is how I perceive a conservationist ethics of disability in the specific context of Tourette Syndrome and of this thesis.

Beyond this, however, I would argue that the ongoing focus on adulthood experiences throughout this thesis – something that is missing from the majority of existing literature on Tourette Syndrome – is in line with Garland-Thomson's *conservationist ethics of disability*. In my understanding, a conservationist ethics of disability considers service provision that aims to *conserve* the people. As per a common point in this thesis, Tourettic children become Tourettic adults (despite what you might derive from trends in published

literature). Conserving Tourettic people, then, requires thinking through Tourettic ageing. Tics might influence balance, which increases fall risk for elderly Tourettic people. We must think about the long-term impacts of Tourettic embodied experience in likely increased potential for the development of arthritis or even connective tissue problems. Perhaps it is an ambitious stretch to jump from questions of the ideal public space, to broad abstract ideas of conservationist ethics, and back to the hyper-specific example of ageing with Tourette Syndrome. However, there are ways in which we can think through these points in moving towards practically applying this conservationist ethics in the specific instance of Tourette Syndrome, with ageing as an example in mind. Thinking through Garland-Thompson's proposed conservationist ethics of disability raises more questions about the intersectional approaches we need in order to be able to imagine these Tourettic spaces of the future.

With this in mind, I do not believe that this thesis offers a particular hopeful future for Tourettic people. Rather, this research provides a clear foundation upon which further inquiry needs to happen. Beyond the discussions of *ideal* public spaces and of a conservationist ethics of disability there are, vitally, some distinct suggestions and recommendations that can be made for Tourette Syndrome research and for Tourette Syndrome service provision based on the findings of this research, and they must be addressed in order to allow us to move closer to these hopeful imaginaries of Tourette Syndrome.

### **7.2.1 Initial steps and recommendations**

Taking these smaller steps towards hopeful futures are important. Whilst I may have stated a controversial point that this thesis and its findings do not necessarily provide specific and immediate hopeful futures, there are still some key steps that might push us forwards in being able to imagine them in clearer ways. These can be split most simply into recommendations for Tourette Syndrome research, and for Tourette Syndrome service provision. These recommendations stand true whether the service providers in question are based in a professional healthcare setting or facilitated by charitable organisations. This section shall outline some specific recommendations to move us forward and outline the ways that these two areas of recommendation are deeply intertwined.

### Recommendations for Tourette Syndrome Research

At this point in the thesis, it is no groundbreaking point to state that my opinion of previous Tourette Syndrome research is not the most positive. Tourette Syndrome research has a history of infantilisation and erasure, which were two things that I had initially raised as points I wanted to address at the outset of this project. The work that centres Tourettic people is sidelined. In this instance, by people I mean to specifically refer to the Tourettic *people* (not individuals) as a collective community. This thesis has led me to ask myself one question in particular, regarding research as a conversation point: Where is the *Tourettic* in Tourette Syndrome research?

In thinking through the lack of Tourette Syndrome research that centres tourettic people, I came to realise that my concern is with the focus on researching Tourette Syndrome, rather than researching *the tourettic*. Tourette Syndrome research often finds its home in psychiatry, psychology, neurology, and so on – never in Tourette Syndrome specific journals<sup>39</sup>. As a result, the focus of TS research tends to be on the Tourette Syndrome, rather than on *Tourettic* experiences, culture(s), and so on. The research is on Tourette Syndrome, not on the person who experiences it. Ultimately, Tourette Syndrome research would do well to respond to calls for the centring of Tourettic people (Bervoets et al., 2023).

This thesis in particular centred Tourettic people not only in the simple act of hosting advisory focus groups to determine the scope of the research and drew inspiration from participatory research methodologies, but through incorporating Tourettic people in every stage of the project. Tourettic people were consulted in research inception, in data collection, in data analysis, and even in dissemination (or non-dissemination) of findings. Through doing so, the research represents what matters to Tourettic people, and not solely to the non-Tourettic stakeholders in Tourette Syndrome, be they family members, clinicians, psychiatrists, and so on. Through taking this person-centred approach, I argue that I have used what I refer to as a *Tourettic studies* approach to Tourette Syndrome research in that the people who are the most affected are the ones who lead the narrative and the discourse – something which I have argued should be the case regarding disability more broadly speaking elsewhere (Jones & Gauthier-Mamaril,

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<sup>39</sup> At the time of writing (2024), there are no Tourette Syndrome specific academic journals that exist internationally.

2024). In this thesis, centring Tourettic people has looked like respecting the language that participants use to describe themselves and making intentional decisions to mirror that - whether disabled, neurodivergent, or something else entirely. It has also included the conceptual focusing on the zineing workshop space rather than a deep analysis of the zine that was produced. This centring of Tourettic people as leaders, not consultants, is something that I believe is missing from current Tourette Syndrome work and I believe that many of the concluding points and conceptualisations of the ways in which Tourettic adults experience public space(s) in embodied ways would not have come to fruition without this approach.

For example, in *Chapter 4: Chance Encounters: The Social Dynamics of Impulse and its Cycles* we came to understand the creative strategizing work that takes place by Tourettic adults that is key to the management of chance encounters. The adopting of this person-centred approach to the research that I argue is missing elsewhere was instrumental in allowing us to draw these conclusions and to be able to conceptualise the ways that Tourettic adults interact with public spaces in this way. Through focusing on centring the Tourettic people in this project, we were able to move beyond mere discussions of the suppression of tics that overpopulate the literature (Himle & Woods, 2005; Kawohl *et al.*, 2009; Kim *et al.*, 2019), and consider more nuanced ways that strategizing that takes place in the management of chance encounters. It goes far beyond the suppression of tics, and is significantly reliant on individual approaches to navigating space and place, and smaller, more subtle strategies such as the redirection of gaze by acting as if you are looking for the source of a tic that Kacy highlighted (Kacy, Interview 1). Similarly, in *Chapter 5: Tourette Syndrome, Public Space and the Importance of Community* we see the nuanced discussion of digital spaces and the ways in which this strategizing persists into digital spaces. Focusing on the *Tourettic* experiences here rather than on the Tourette Syndrome moves us from making suggestions about digital treatment options and statistics on isolation (Hollis *et al.*, 2021) towards a significantly better understanding of the complex ways that the digital realm is experienced and managed by Tourettic adults, and the ways in which individual experiences had in these spaces contrast with one another. In the contrasting of these experiences, it raises more questions about the intersectional experiences of these spaces. Considering gender, ethnicity, sexuality and so on is something that is significantly missing in broader Tourette

Syndrome literature, partly as a result of the lack of centring the most affected – Tourettic people ourselves. Additionally, the entirety of *Chapter 6: Creative methodological contributions to hopeful futures of tourettic belonging* had its focus on the zine workshop as a site for solidarity, which reflected the interests of the participants. The reflections on the workshop would not have been so developed had Tourettic people not been centred in their desires and own interests for this project.

With this in mind, the centring of Tourettic people and the study of the *Tourettic* rather than of the ‘condition’ of Tourette Syndrome from a clinical perspective is something that we need to continue to employ in order to move TS research forwards. Perhaps there is a case to be made for a new *Tourettic Studies* that has this distinct focus, similarly to the ways in which Critical Autism Studies and Critical Disability Studies disciplines came into existence (cf. Goodley *et al.*, 2021). Perhaps a *Tourettic Studies* might take this aforementioned conservationist ethics approach, whereby we seek not to *treat or remove* Tourette Syndrome as a way of being in the world but rather seek to better understand the Tourettic aspects of the world in which we live in.

#### Recommendations for Tourette Syndrome Service Provision

This leads on to specific recommendations for service provision – being person centred. Tourette Syndrome services are significantly influenced by academic research and discourse. With the lack of a person-centred (or a *Tourettic studies*) approach to much of the research, it is the most affected who are oftentimes the most neglected. The *Nothing About Us Without Us* approach should also apply here to service provision - *Nothing For Us Without Us*, perhaps might also be a relevant approach here. Are adult support services really *for* Tourettic adults when the adults are viewed as the pariah of care, support and promise that children’s lives won’t be inevitably terrible because of a Tourette Syndrome diagnosis (cf. Leesh, Interview 1)? The recommendations that arise as a result of this research are largely focused around the centring of Tourettic people as a priority and as something that seems to be missing at the moment. With this in mind, this research provides grounds for 3 key recommendations for service providers<sup>40</sup>:

#### **1. “It’s not always about you”**

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<sup>40</sup> Additional to these 3 key areas of recommendations for service providers, a more detailed briefing was produced and provided to this research’s charity collaborators TIC-Hull.

This is a phrase that I have used in various settings, including conferences, that has caused some push-back, hushed gasps, and shaking heads. However, this thesis' previous use of the concept of performing body-absence (cf. García-Santesmases *et al.* (2022) highlights the importance of this reminder. With non-tourettic stakeholders in Tourette Syndrome posting videos of children ticcing where they air their frustrations, their worries of poor future quality of life, and so on, these online spaces become *for* the non-Tourettic stakeholders in Tourette Syndrome.

A key example from the research data that highlights this is through River's explanation of the ways that the funding for online adult support groups was cut to make way for the facilitation of support groups for 'siblings of people with Tourette Syndrome' (River, Interview 1). Tourette Syndrome support services have lost sight of what they were supposed to be – *for Tourettic people*. Non-Tourettic people need to remind themselves that Tourette Syndrome support services are not primarily for you. These services *should* be for Tourettic people as a priority. Tourette Syndrome support services should take a people centred approach and centre the most affected – *Tourettic people*. Once more, seeing these changes in research would also have a knock-on effect in improving the situation in terms of the service provision that exists. However, there are ways to prioritise Tourettic people that don't always require additional funding. This might be through the moving around of funding pots – something which is very much possible in regards to the sources of funding such as charitable donations – or even in the simple act of prioritising physical space in venues such as TIC-Hull's *The Hub* for Tourettic people (specifically adults in this instance). Tourettic adults should be prioritised in Tourette Syndrome support services above the non-tourettic parents of Tourettic children. This *should not* primarily be about non-Tourettics, but it oftentimes ends up being this way.

Tourette Syndrome support service providers should make active attempts to support, once more, Tourettic people as a first point of call. This might look different in different contexts and in different organisations, but there should be commitments made to have this Tourettic-centred approach to Tourette Syndrome support moving forward.

## **2. Communications about Tourette Syndrome should not *other* Tourettic people**

This is a key recommendation that has come up time and time again throughout the course of this thesis, notably the instance of continuous non-consensual positing of

children ticcing in social media facilitated spaces. In particular, Sugar Tits discussed frustrations surrounding the ways that non-Tourettic parents of Tourettic children talk about their children:

*they air on the side of negativity, and it's all about "Oh, my poor baby it's so, so hard to watch him"*

- Sugar Tits, Interview 1

Posting videos of children ticcing is very much in line with a clinical approach to Tourette Syndrome. It is a very common practice at medical conferences to show potentially triggering videos of TS patients ticcing in spectacularised ways, where the person is not centred. The practices happening in community-organised and advocacy spaces of sharing these videos has an effect on the practices in these medical conferences: "If advocacy groups do it, it's fine for us to do the same, right?" Whilst medical spaces have been doing this for a long time, the practices in advocacy and support spaces only reaffirm the attitude that this approach is appropriate. The focus on the tics and the approach of capturing and *disseminating* tics in this way is an incredibly dehumanising practice, particularly when done by non-Tourettic stakeholders in Tourette Syndrome. This clinical approach removes the important centring of the Tourettic people, and promotes seeing Tourettic people as inhuman, as *other*, as *spectacle*. On the other hand, as per Sugar Tits' account, the "*my poor baby*" approach to these posts and shared videos is just as othering. Adopting this 'charity model' of disability and imposing an identity and a narrative of victimhood on the person ticcing is just as dehumanising as the clinical practice of not seeing the person, but seeing the tics first and foremost. Tics are deeply personal. They are felt in incredibly emotional and political ways, whether in relation to the inner conflicts of having transphobic tics as a transgender person themselves and the ways that this has an impact on feeling required to disclose as not only Tourettic but also as trans (River, Interview 1); the concerns over race-based derogatory tics and worrying about being perceived as racist (Bella, Interview 2), or otherwise.

Whilst the collection and showcasing of tics in this way this can be well-meaning, this often results in further stigmatisation and the spectacularization of Tourette Syndrome and associated symptomologies. It is exploitative and is often done without the consent of Tourettic children, oftentimes being too young to be using social media platforms and resultantly not even knowing that their tics are being posted online for people to watch.

One key problem with this is that charities and support services in particular oftentimes can be found asking for these kinds of videos to be posted to either *show people that they're not alone* (which by 'people' they mean the parents of Tourettic children, rather than Tourettic people themselves), or because they need content for awareness-raising campaigns, social media posts, and so on that can contribute to the victim narrative in order to stand a better chance at being awarded the already very limited funding for these services that does exist.

Whilst the intentions behind these practices are not malicious, the impact they can have is profound. It contributes not only to the othering of Tourettic people in online spaces, but also within the in-person support services that may be provided by the same organizations. It is very common practice for members of the Tourettic community to be diagnosed, discharged immediately, and left to fend for themselves. This leads to the digital shift in support-seeking outlined in Chapter 5, meaning that these spaces of othering through the simultaneous clinicalization and spectacularization of Tourette Syndrome are oftentimes the first spaces that Tourettic people find themselves engaging with. They are advertised as being a space of support, but support may well not be found within them. Within TIC-Hull's staff and trustee board teams, there have been discussions through our collaboration about the concerns with translating online membership of support groups to the in-person attendance of support groups, and I argue that these othering practices are a key part of the problem here. Yes, there have been digital shifts due to the minimal services available meaning that people cannot travel to in person support groups due to the living significant distances away from any kind of support. Yes, there has been a digital shift particularly following the COVID-19 pandemic and the onset of isolation and lockdown policies in the UK. However, we must not fail to acknowledge that there are digital practices of othering that play a role here too that perhaps make people less comfortable with the idea of attending in-person support. The felt effect of othering in digital spaces lingers in Tourettic bodyminds, and causes concern over attending in-person support groups. This is not only an issue that has been discussed in the context of TIC-Hull, but of Tourette Syndrome charities and service providers across the UK more generally speaking too. Othering practices make these spaces of support unable to offer support to those who are the most affected, and this is something that is

key to address. There is work to be done in undoing the way we approach tics and the practices that are deemed acceptable in these spaces.

### **3. Tourettic adults need safe spaces too**

One way that the issues and recommendations highlighted in recommendation 2 might be addressed is through acknowledging that Tourettic children become Tourettic adults, specifically regarding safe space provision. A particularly important conclusion from Chapter 6 was that *activities* are not something that can benefit Tourettic children exclusively. The high praise from the zineing workshop participants within this project speak to this – the zine was not the important thing to them, it was the space that the workshop offered for facilitating solidarity, community building, and sense-of-belonging that the aforementioned *othering* practices of service providers have broken down.

A sensory room is all well and good, but why are they exclusively child-sized? Why do organisations host youth groups in their own venues, but only have adult-specific social or community-building activities that happen outside of this safe place? Going to a pub or to the bingo - two common activities that TIC-Hull arrange for the adult community - are not necessarily ones that can be considered safe for people, and TIC-Hull are the rare case of organising *any* activities for adults at all. Hosting activities, such as the zineing workshop, in familiar and safe spaces are important in the ways that they can minimise the extra labour of creative strategizing work that many of the participants in this project shared they engage in when using public spaces.

Ultimately, adults need safe spaces too. Experiences of loneliness linger far beyond the schoolyard. If anything, given the lack of service provision available, we could argue that they have the potential to significantly worsen. Very little, if any, research has been done into the long-term impacts of Tourette Syndrome and its symptoms. Ageing with Tourette Syndrome has been neglected, both in terms of physical and mental health implications. Service providers have a responsibility to step in and provide safe spaces and these services more generally for Tourettic adults if we are to avoid much future work about the poor mental health outcomes of Tourettic ageing.

## **7.3 Disciplinary Implications and Contributions**

### **7.3.1 Research Methodologies**

As a piece of work, this PhD thesis has contributed original and important analyses that have a direct impact on Human Geography as a discipline, as well as on research methodology more broadly speaking. Whilst this work itself could be considered a case against disciplinary boundaries, there are some specific contributions that have been made in the context of the discipline that has hosted this project over the previous 4 years.

Creative activity-based research spaces, such as the zine workshop, in fostering solidarity and in centring Tourettic people as a priority. A discipline that takes methodological design and research ethics very seriously, Human Geography is somewhat known for its creative applications of research methodology in robust, well-thought-out ways. However, there does seem to be something missing when it comes to activity-based, workshop styled methods like the zineing workshop that was facilitated within this project. What my approach to research methodology here highlights is the profound impact that centring the participants can have on the research design. In the case of this research, this centring resulted in advisory focus groups having a key role in determining the general direction of the research, and determined the analytical focus based on participant interests such as the analytical choice of reflecting more on the space of the workshop than the *final product* of the zine *Tic Tic Boom!* itself. Whilst participants may not always be able (or want) to be involved in research funding applications, ethical committee applications, and so on, they can still have an incredibly significant influence over the direction of large pieces of research such as this PhD thesis. As per Chapter 6's comments, the choice to analyse the workshop space rather than the zine content as a priority was something that significantly shaped the project. Following the desires and the interests of the participants *beyond* the research methodology design *can work* – something that many ethics committees may feel uneasy about.

Secondly, research methods do not have to be extractive. The focus for the zineing workshop was not on productivity and making sure that a coherent, clean zine was ready for research dissemination. In fact, the zine did not end up being disseminated beyond the workshop attendees themselves. The focus was on coming together in a joyful environment that we all left at the end of the day with a warmth in our minds and hope for the future. Methodological activities can offer hope, solidarity, and so much more. Research methods can be well thought out and robust, but this does not necessarily mean they have to feel clinical. Methods such as *zineing* can be used in productive ways

beyond the *production of a zine for dissemination* but can also be productive in the ways in which the foster spaces of solidarity, community, and sense-of-belonging.

In summary, the methodological contributions to this thesis are found in the evidencing of the value of focusing on process-based approaches in line with creative research methodologies, as well as the value of flexibility in research. Again, participants were more interested in the workshop space itself, rather than the final zine, and so through listening to the participants' interests, the research went in a new direction that was much more methodology focused.

### 7.3.2 Geographies of Impulse

Beyond methodological contributions, this thesis raises one question in particular for me regarding Human Geography as a discipline. As this thesis asks the question of 'where is the Tourettic in Tourette Syndrome research?' perhaps this thesis is a case for us to ask the question of 'where is the human in human geography?' In a discipline interested primarily in the processes that affect people, are we centring the process over the people? This PhD thesis encourages us to ask this question, and in making a conscious attempt to centre the Tourettic people first and foremost in this work, it has led us to the consideration of what I refer to as a *Geography of Impulse*. After the many analytical points made up until now, some of the questions raised as early as in the introduction of this thesis still remain. Once more:

*"Around 6 years ago, I sat in a seminar for my MA degree in Cultural Geography, as the instructor lectured about the body and how bodies navigate space. She stated that the body's movements are choreographed, each movement being made intentionally and having purpose that arose in response to external stimuli. As somebody with a diagnosis of Tourette Syndrome and therefore with limited control over my own body, this sparked my interest. I grew increasingly frustrated knowing that the only literature I could find didn't feel like it made any sense to me, as somebody who experiences impulse arising from Tourette Syndrome and tics. In an attempt to understand my own body, I ran with this idea of impulsivity in my MA dissertation, and it was revealed to me that there was much more to this line of inquiry than I had initially thought..."*

- (Chapter 1, page 9)

I still feel somewhat similarly, as I now ask myself if I understand my own body. Do I feel represented? Is my body choreographed? Was I wrong? Was I right? What has changed? Has society changed? In the ever-changing landscape of Tourette Syndrome

discourse, these questions still need to be asked. I do not feel represented by the literature that exists. My movement feels somewhat choreographed, but somewhat improvised. With these confusions in mind, the analysis and conclusions drawn in this thesis have offered not only contributions to the discipline, but also to me as a Tourettic person myself. Whilst the answer to these questions may never be able to result in a set-in-stone answer, the *Geographies of Impulse* brought forwards in this thesis are a strong first step to addressing them. Geographies of Impulse – or Impulsive Geographies – acknowledge the strange in-between space of improvisational versus choreographed movements and use of public space. Whether in the creative and impulsive ways of dealing with public space's general detest of *otherness* that are illustrated in the variety of chance encounters to be had; the impulsive ways in which Tourettic people feel drawn to, or pushed away from, online means of support and community; or even in the impulsive interest of research participants whose interest was peaked in specific moments or points raised in focus groups, interviews, or the zine workshop that shifted the focus of this thesis, the Tourettic experiences of public spaces are underwritten by a geography of impulse. Moving beyond the medicalised approach to, and view of, Tourette Syndrome offers up this new geography(ies) of impulse. Ultimately, in the case of Tourette Syndrome and public space, *Geographies of Impulse* highlight the distinctly impulsive experiences that are inherent to the Tourettic lifecourse. In a condition somewhat defined by the variety of symptomology and experience, the constant is, in this case, impulse.

The crippling of public space in geography has previously looked at, in short, challenging ableist norms about public spaces by working towards a fostering of inclusivity in and around public space. This thesis offers an alternative crippling of public space that is specific in highlighting the distinct embodied experiences of Tourettic adults in and around public spaces. In this thesis, considering crip bodyminds and the ways in which geography has previously considered interactions between them, the ways in which Tourettic bodyminds interact with each other are distinct in their impulse and deep connection, such as through the suggestibility of tics, and have profound influences on broader mobility practices. This nuance specific to Tourette Syndrome considers crip and geographical approaches to disabled bodyminds in new and innovative ways, including but not limited to questions around differing experiences of 'crip time' (Katzman *et al.*,

2020) for impulsive bodyminds specifically, and not just for disabled bodyminds generally speaking.

Conceptually, this thesis fills a gap that makes space for new approaches for geographical consideration of Tourette Syndrome. To return to non-representational theory, encounters are considered as vital in place-making (Boyd, 2017) and this thesis highlights some of the ways that these encounters and their influences on placemaking are particularly distinct in the case of Tourette Syndrome. In doing so, it introduced the concepts of both ‘chance encounters’ and ‘pockets of opportunity’ in order to allow us to progress research into Tourette Syndrome. In offering a representational approach and a departure from the Geographies of Disability in order to ‘catch up’ with non-representational theory approaches, the thesis offers a stepping stone for Tourette Syndrome research to develop with greater nuance and intersectional understanding than has been done before. The Geographies of Impulse is a distinctly Tourettic approach to crip geographies of disability and public space, and raise even broader questions about the relevance of impulse and impulsive bodyminds in general, highlighting a need for further inquiry into these in both physical and digital public spaces.

### **7.3.3. For Tourettic studies**

However, something is still missing. Throughout this thesis, my frustrations have been aired about the focus on non-Tourettic stakeholders in Tourette Syndrome. The same goes for many of the participants. Tourette Syndrome discourse, in its current state, does not centre the most affected (Tourettic people ourselves). What might this mean for a focus on the *Tourettic* moving forwards? What new insights might arise from this centring of Tourettic people, cultures, experiences? This is not something that seems to be happening in TS research in the same way that this thesis approaches the *Tourettic*. Even the very word Tourettic is controversial within TS research spaces (Jones, 2023; Ne’eman, 2023).

My hope for a *Tourettic Studies* would be a space that is inclusive for Tourettic people first and foremost. Tourettic people *must* be at the heart of everything we do when it comes to Tourette Syndrome research. There is a time and a place for medical, clinical research into genetics and so on. There is also power and impact found in the sharing of individual stories. However, we need a space for the consideration of more-than-experience and

more-than-clinic to come together and not just work in individually interdisciplinary ways, but rather to actively work to *interdiscipline* processes, concepts, theories, and so on. A *Tourettic Studies* would actively engage in the act of *interdisciplining*, centre Tourettic voices as a priority (not non-Tourettic stakeholders in Tourette Syndrome), and be committed to a disability justice approach that does not make comparisons to punch down at other areas of research and other marginalised communities – cross movement solidarity is key. This PhD thesis has given way to not only a Geography of Impulse, but a Geography of Impulse has offered what I consider a hopeful future of *Tourettic studies*. The Tourettic experiences of public space are distinct, and this distinction comes in many forms. Through focusing on the *Tourettic* rather than the Tourette Syndrome, we can come to acknowledge the *Tourettic* ways in which public spaces are used, navigated, and experienced more generally speaking in ways that move beyond disabled experiences being defined by *social difference*. A Tourettic Studies approach might consider the intersectional ways in which Tourettic people experience public spaces in a diverse range of embodied ways, without relying on the narrative of difference to justify it them.

#### **7.4. Concluding Remarks**

Lessons can be learned from the stories of hurt and joy and loneliness and solidarity that are featured in this thesis. Tourettic experiences are kaleidoscopic. They are chaotic and ever changing and contrasting and *in flux*. The findings in this thesis offer simply a starting point – and hopefully a turning point – for brighter futures with the kaleidoscope of Tourettic experience in mind. This PhD thesis offers significant and original contributions to Tourette Syndrome discourse, research and advocacy. With a Tourettic-centred approach that gives way to a Geography of Impulse, what comes next? Perhaps we acknowledge that Impulsive Geographies might offer more to the study of public spaces, with ideas of chance encounter and inherent human impulsivity in mind. All that is for sure, is that the question of ‘what next?’ is a huge question indeed. All that can be said is that it cannot be done in isolation, by me or any other academic, Tourettic person, or otherwise. If we are moving towards a *Tourettic studies*, whatever that may be, it needs to be led by *us*. That is my hope, and sense of positive expectation for the future. Only through centring the most affected in solidarity-focused ways will we reach this hopeful future imaginary of Tourette Syndrome discourse.

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## Appendices

**a. Consent form (1 page)**

CONSENT FORM



## Consent Form for Participants

Project Title: Geographies of Impulse

Researcher: Daniel Jones (PhD student at Newcastle University)

Have you received and read the information sheet? \_\_\_\_\_ Yes | No

Have you received enough information about the study and had opportunity to ask questions? \_\_\_\_\_ Yes | No

Are you happy for research data (including but not limited to artwork, interview recordings, and tic diary entries) to be collected and used for the purpose of this project? \_\_\_\_\_ Yes | No

Are you happy for personal data (including but not limited to name and contact information) to be collected and kept for the duration of the project? \_\_\_\_\_ Yes | No

Have you been informed that all data will be stored confidentially, and will be deleted after the project's completion? \_\_\_\_\_ Yes | No

Do you consent to occasionally being contacted in relation to your participation in this project until completion? \_\_\_\_\_ Yes | No

\_\_\_\_\_

I confirm that I am 18 years of age or older \_\_\_\_\_ Yes | No

Do you understand that participation is voluntary and that you can withdraw from the study at any time without need to give reason? \_\_\_\_\_ Yes | No

Do you agree to participate in this study? \_\_\_\_\_ Yes | No

Do you have any accessibility requirements and/or adjustments that you may need, and wish to make the researcher aware of? (If none, please leave blank)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Participant Name: \_\_\_\_\_ Researcher Name: \_\_\_\_\_

Participant Signature: \_\_\_\_\_ Researcher Signature: \_\_\_\_\_

Date: \_\_\_\_\_ Date: \_\_\_\_\_

**b. Information Sheet (3 pages)**



## GEOGRAPHIES OF IMPULSE

A STUDY OF TOURETTE SYNDROME AND THE EMBODIED EXPERIENCES OF PUBLIC SPACE

My name is Daniel Jones and I am a PhD student at Newcastle University, working in collaboration with the charity TIC-Hull. I am studying how Tourettic people experience and interact with public spaces, and what the influencing factors of that are.

I invite you to join this project, and to take part in a research study! Before agreeing, please do have a read of the information about the study found below, which includes what it involves and what the aims are, and discuss it with others if you wish. Please also feel free to ask me any questions you might have, especially if anything is unclear, you need additional information, or have any questions regarding accessibility.

### Who can be involved?

All adults (18+) who have a diagnosis of Tourette Syndrome, are in the process of seeking a diagnosis of Tourette Syndrome, or have a self-diagnosis of Tourette Syndrome are invited to take part in this study. This includes those with are childhood-onset ticcors, as well as those who have adulthood-onset. Some parts of the project will take part in-person in Hull, and so require you to live within a commutable distance from TIC-Hull's main base (Ings Resource Centre, Savoy Road, Hull HU8 0TX). However, for those further afield, there are plenty of other opportunities for you to be involved too!

### About TIC-Hull

TIC is a charity based in Hull, UK who work to support local people who are affected by Tourette Syndrome / tic disorders and co-occurring conditions that impact on mental health and development. They provide awareness talks to schools and organisations that may need to develop a better understanding of the condition in order to support their service's users. They also provide a safe and non-judgemental place for people to come and seek advice and support, and for people to learn about Tourette Syndrome and other tic disorders.

### What is involved in taking part?

There are multiple aspects to the study that feed into each other. However, it is not compulsory to take part in every single activity shown below – please feel free to be as involved as you feel comfortable.

**FOCUS GROUP:** A series of initial focus groups will occur at the start of the project, which will help to fine-tune the direction of the project. These will last for around 1 hour each, with some taking place at TIC-Hull's base in Hull, and some occurring through online platform 'Zoom'.

**TIC DIARIES:** Participants will conduct a series of 'Tic Diaries', which are diary/journal-like activities whereby you write at least one entry per day, at whatever length you are able to, about your experience of Tourette Syndrome in relation to the activities you undertook that day. We suggest that each entry be accompanied by a photograph, which you can take on your phone. Anybody will be able to take part in this project, regardless of where you live.

**CREATIVE WORKSHOPS:** A series of creative workshops where we discuss tic diaries and our experiences of living with Tourette Syndrome as adults, and use those discussions as prompts to

## RESEARCH INFORMATION SHEET

create artwork. We will seek to publish artwork in the form of a Zine (independently produced magazine). To participate in this activity, you will need to live a commutable distance from TIC-Hull's main base (Ings Resource Centre, Savoy Road, Hull, UK, HU8 0TX).

**INTERVIEWS:** We will also be conducting individual interviews about the experiences of public space. These will take place over Zoom, meaning that anybody is able to take part.

### What kind of data will be collected about me?

**RESEARCH DATA:** I would like to take a mixture of data from across all of the activities, including written field notes and audio-recordings of interviews and focus groups. We will always ask you if you are happy for us to start recording – the collected data will be used as reference for us to look back on in the later stages of the project, helping us to analyse our findings. Without this data, it is difficult to accurately write about what was said and done, so it is necessary. However, data will be anonymised.

**PERSONAL DATA:** Personal data such as name and contact information will be collected so that contact will be able to be made throughout the duration of the project. This information will be stored confidentially and will be securely kept, only accessible to me.

### What will happen to the information collected about me?

**PRIVACY:** All data will be kept and only used for the purpose of this project – data will be anonymised and kept securely and confidentially, only accessible by the research team. For example, audio-recordings will be transcribed and anonymised using pseudonyms.

**CONFIDENTIALITY:** The only time that confidential information may be shared is when necessary as in the case that you have indicated that you are at risk of being harmed, in danger, or going to cause yourself or someone else harm. For any unnecessary sharing of data, I will always ask for consent first.

### What are the benefits and risks of taking part?

**BENEFITS:** You will be involved in research that may lead to changes in policy to make public space more accessible for those with Tourette Syndrome. Further to this, you will have the opportunity to connect with a wonderful community of fellow Tourettics, and also hopefully have a lot of fun in creating art. Further to this, you will have the opportunity to have art published in a Zine too!

**RISKS:** Some of the topics of discussion that come up may be quite sensitive in nature, but you are welcome to share as much as you feel comfortable with. Also, the nature of Tourette Syndrome means that if you are around other people with tics, you may *pick up* some new tics. However, there is absolutely no pressure to stay in any spaces in which you feel uncomfortable, and you are welcome to leave/return at any time.

### What happens if I do not want to continue with the research?

**WITHDRAWAL:** If you decide to withdraw from the project, I will delete all personal information and information that has been collected from you, that removes anonymity. For reference, anonymised data will still be kept but will not be used or directly quoted in any publications.

**ASSUMED WITHDRAWAL:** In the instance that you are not contactable or responsive to attempts to communicate, the following procedure will be followed:

#### RESEARCH INFORMATION SHEET

**STEP 1:** You will be sent an email 2 weeks after being initially contacted, asking whether you had read the previous communications.

**STEP 2:** You will be sent an email 2 weeks after step 1, asking if you still wish to participate in the study

**STEP 3:** After one month following step 2, I will email to confirm assumed withdrawal from the study and redaction from any data/research as a part of this project, but remind you that you are welcome to get in touch should you wish to remain involved in the remainder of the research project.

#### Who is the research team involved in this study?

Researcher	Daniel Jones	d.jones9@ncl.ac.uk	Newcastle University
Supervisor	Robert Shaw	robert.shaw2@ncl.ac.uk	Newcastle University
Supervisor	Caleb Johnston	Caleb.johnston@ncl.ac.uk	Newcastle University
Supervisor	Janice McLaughlin	Janice.mclaughlin@ncl.ac.uk	Newcastle University
Charity	TIC-Hull	enquiries@tic-yorkshire.co.uk	Newcastle University

#### Thank you for taking the time to read this information

If you have any questions or concerns, please feel free to contact Daniel Jones

Email: [d.jones9@newcastle.ac.uk](mailto:d.jones9@newcastle.ac.uk)

Phone: +44 7827 983570

#### Support networks

If taking part in this study raises any specific concerns, please consider contacting the relevant organisations below.

TIC-Hull | [enquiries@tic-yorkshire.co.uk](mailto:enquiries@tic-yorkshire.co.uk)

Tourettes Action Helpline | 0300 777 8427

The Samaritans | Mental Health | 116 123

Mind | Mental Health | 0300 123 3393

**c. Risk Assessment (11 pages)**

## School of Geography Politics and Sociology Travel Risk Assessment

Travelling without appropriate risk assessment may prejudice subsequent insurance claims

**\*\*One copy of your signed RA must be left with the GPS School Safety Officer.\*\***

Send risk assessment to: [gps.safetyofficers@ncl.ac.uk](mailto:gps.safetyofficers@ncl.ac.uk).

### Traveller

Name	Staff/ student Number	School	Unit	Telephone mobile & landline	E-mail University and/or personal	Next of Kin (Name and contact details)
Daniel Jones	190571661	GPS	Geography	M: 07570793771 W: 07827983570	<a href="mailto:d.jones9@newcastle.ac.uk">d.jones9@newcastle.ac.uk</a>	Joanna Jones 07931274409

Add more rows for additional travellers

### Project or Module

Title	Summary (Please provide a summary of your work activity/ project/ research which requires you to travel)
Geographies of Impulse (PhD Human Geography Thesis)	Travelling to TIC-Hull (collaborative charity partner) offices in Hull to conduct workshops and interviews for research

### Emergency Contacts

<a href="#">Insurance</a>	<b>AIG insurance tel: +44 (0)1273 552 922</b>
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<a href="mailto:insurance@ncl.ac.uk">insurance@ncl.ac.uk</a> Tel: +44 (0) 191 208 6520	<ul style="list-style-type: none"> <li>Staff &amp; Post Graduate Students- policy number: 0010628132</li> <li>Undergraduate Students- policy number 0010628143</li> </ul>
<a href="#">Selective Travel Management</a>	Routine - 028 9044 2071 (8.30am- 6pm) <a href="mailto:ncl@selective-travel.co.uk">ncl@selective-travel.co.uk</a> Emergency - +44 7720 593700
<a href="#">British Embassy</a> <a href="#">Please note for staff/ students who are not UK nationals please enter your own Government embassies in this section.</a>	N/A
<a href="#">In Country Emergency Services</a>	999 for emergency services 111 for health advice
In country guide/ local contact during trip (Address/ e-mail/ mobile/ landline)	Kim Mitchell (TIC-Hull)   07449338515
Newcastle University Contact <ul style="list-style-type: none"> <li>PI/Module Leader/ Line manager/ supervising academic/office</li> <li>Security +44 (0) 191 208 6817 (24 hours) <a href="mailto:security.control@ncl.ac.uk">security.control@ncl.ac.uk</a></li> </ul>	Rob Shaw, Caleb Johnston & Janice McLaughlin

## Foreign and Commonwealth Office (FCO) Travel Advice

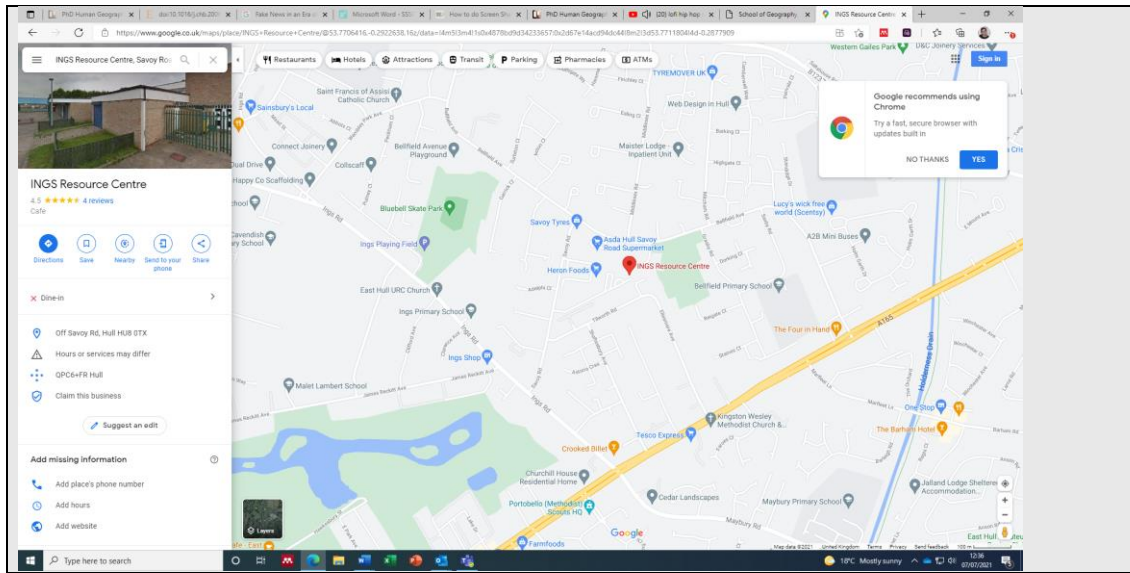
What is the [FCO travel advice](#) for your destination(s)? For trips to more than one country please tick all the levels of travel advice which apply for all the countries you are planning to visit.

FCO advice categories	Copy of web link to FCO travel advice	Destination Country Please name all destination countries
<input type="checkbox"/> Advise against all travel (red) No staff or students are permitted to travel to these destinations.	N/A	N/A
<input type="checkbox"/> Advise against all but essential travel (amber/ orange)	N/A	N/A

UG students are not permitted to travel. PG students and staff may travel but the risk assessment <b>must</b> be approved by the Pro Vice Chancellor.		
<input type="checkbox"/> See FCO travel advice before travelling (green) Students and staff may travel having regard to the FCO travel advice	N/A	N/A

## Itinerary

Field Location(s)	
Location: TIC Hull Offices INGRS Resource Centre, Savoy Road, Hull HU8 0TX	
Map	



## Risk Assessment

Does this travel and activity present a significant risk to safety?

Yes  No

*(You must still identify all relevant hazards & risks below, even if you tick 'No'. Common hazards are suggested below, but add additional hazards if needed)*

When carrying out the risk assessment the following hyperlinks will provide useful information:

- [Occupational Health and Safety Service](#)- University policy, guidance and risk assessment form
- [UK Government Foreign and Commonwealth Office \(FCO\)](#)- country specific travel advice
- [Control Risks](#)- a more detailed travel advice service purchased by Newcastle University (staff only)

- [UK Government - Travel Health Pro](#)- country specific advice on all aspects of health and vaccinations
- Refer to the GPS Field Safety Guide and the GPS Researcher Handbook for information on common fieldwork hazards in Physical and Social Sciences <http://www.ncl.ac.uk/gps/internal/safety.html>

What are the hazards (bold text)/ risks (bullet points)?	What controls have you put in place?
<p><b>Accommodation</b></p> <ul style="list-style-type: none"> <li>• Physical defects</li> <li>• Risk of fire</li> <li>• Risk of robbery, physical or sexual assault</li> <li>• Terrorist incident e.g. bomb</li> <li>• Falls from balcony's</li> </ul>	<ul style="list-style-type: none"> <li>• There will be no overnight stays in Hull. I will be staying in my own property in Fenham, Newcastle upon Tyne throughout the process. I will be sure to pay attention to roads, to be aware of security measures needed to be kept in place such as setting burglar alarms in the property, and stay familiar with any fire hazard risks throughout.</li> </ul>
<p><b>Work activity</b></p> <ul style="list-style-type: none"> <li>• Risks from work activities including fieldwork e.g. <ul style="list-style-type: none"> <li>○ Operating machinery</li> <li>○ Hazardous substances</li> <li>○ Lone working</li> <li>○ Hazardous equipment</li> <li>○ Transporting heavy samples/ equipment</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>• I am first aid trained and there will be a first aider (physiological and mental health) on site at all times.</li> <li>• I will ensure the space has no trip hazards, and is accessible for all participants including adequate lighting conditions, ventilation, catering (in line with any allergies) etc</li> </ul>
<p><b>Travel and transportation</b></p> <ul style="list-style-type: none"> <li>• Risk of theft/ attack during transfers to and from airport and on public transport</li> <li>• Accident whilst self-driving</li> <li>• Incorrect driving license</li> <li>• Hiring a vehicle and driver</li> <li>• Poor road infrastructure</li> <li>• Density of traffic</li> <li>• Poor driving standards</li> <li>• Poorly maintained vehicles</li> </ul>	<ul style="list-style-type: none"> <li>• Travel will take place via a private vehicle (car), which will be insured and have road tax paid, as well as be kept up to date on MOT and servicing.</li> <li>• I will ensure that driving is done legally, including not driving in bus lanes, not using a mobile telephone whilst driving, not exceeding the speed limit, etc. I will also use a SatNav to ensure I am driving the correct way. I will also only be driving my own vehicle, and so there is not risk of driving a vehicle without the correct license.</li> </ul>

What are the hazards (bold text)/ risks (bullet points)?	What controls have you put in place?
<ul style="list-style-type: none"> <li>Lack of emergency services</li> </ul>	<ul style="list-style-type: none"> <li>I will be aware of hospitals and health centres along the route between Newcastle upon Tyne and Hull, to ensure that I am aware of the closest services if needed.</li> </ul>
<p><b>Location and or regional factors</b></p> <ul style="list-style-type: none"> <li>Crime- risk of robbery/ physical or sexual assault</li> <li>Terrorism or kidnap</li> <li>Political instability</li> <li>Remote working</li> <li>Poor communications</li> <li>Religious tensions</li> <li>Cultural misunderstandings e.g. clothing, alcohol or behaviour</li> <li>Natural disasters e.g. floods/ cyclones/ earthquakes</li> </ul>	<ul style="list-style-type: none"> <li>I will share my location with friends and colleagues via WhatsApp messaging platform, so that my whereabouts are known to all. In order to allow this, I will ensure that my phone is fully charged and that I carry a portable charger with me throughout the duration of fieldwork visits.</li> <li>I will ensure that I carry as few valuables as possible when walking between my vehicle and the site. There is parking on the site, so the distance I will need to walk with valuables or confidential information will be very limited.</li> <li>When working remotely, such as during transcription, or interviews that take place via Zoom, I will ensure that my desk setup is adequate considering things such as my posture when sitting, the height of the chair and desk I am using, monitor height, and so on.</li> <li>When interviewing via Zoom, I will be sure to do so in a private space, and to wear headphones in order to maximise confidentiality. I will also encourage the participants to find a private, quiet space also so that they feel comfortable and are not likely to be overheard.</li> <li>When interviewing in person, at TIC-Hull's offices I will be sure to use a private meeting room.</li> <li>I will make use of the SafeZone smartphone application recommended by the University throughout the duration of the project. (<a href="#">SafeZone App</a>)</li> <li>When conducting research at TIC-Hull's offices, I will adhere to all existing health and safety procedures and protocols that TIC-Hull already have in place.</li> </ul>
<p><b>General health/ environmental factors</b></p> <ul style="list-style-type: none"> <li>Extreme weather</li> </ul>	<ul style="list-style-type: none"> <li>I will ensure that I stay fed and adequately hydrated throughout the fieldwork, including always carrying a reusable water bottle.</li> </ul>

What are the hazards (bold text)/ risks (bullet points)?	What controls have you put in place?
<ul style="list-style-type: none"> <li>• Food and drink (poor hygiene)</li> <li>• Infectious diseases (some requiring vaccinations)</li> <li>• Biting insects or animals including risk from rabies &amp; malaria</li> <li>• Poor or distant medical facilities</li> <li>• Sexually transmitted diseases</li> </ul>	<ul style="list-style-type: none"> <li>• I will carry hand sanitiser on me at all times in case there is limited access to bathroom facilities to wash my hands.</li> <li>• I will not partake in any sexual activity whilst on fieldwork.</li> <li>• I will ensure that I am aware of the closest medical facilities to me at any given time during the fieldwork.</li> <li>• When at TIC-Hull's offices, conducting interviews or workshops, I will clearly point out fire exits, and be sure to tape down any loose cables/other trip hazards to minimise risk.</li> </ul>
<p><b>Individual factors</b></p> <ul style="list-style-type: none"> <li>• Disability</li> <li>• Level of cultural awareness</li> <li>• Inability to speak Language</li> <li>• Cultural/ religious or sexual orientation</li> <li>• Pre-existing medical conditions or mental health conditions requiring management</li> </ul>	<ul style="list-style-type: none"> <li>• All participants and members involved in the research process are aware of my disability (Tourette Syndrome) and so measures have been put in place by the charity to ensure safety. In the unlikely case that I were to have a period of heightened 'ticking' that caused me to need to step away, there is a quiet and safe space I can go to 'take a break'.</li> </ul>
<p><b>Specific FCO advice</b> (overseas travel only)</p>	<ul style="list-style-type: none"> <li>• N/A</li> </ul>
<p><b>Other hazards such as COVID -19 DETAILS</b> Please change hazard title and enter additional hazard(s) as required.</p>	<ul style="list-style-type: none"> <li>• To respect and protect others, I will wear a face mask/covering or visor. This is no longer a requirement by the UK government, but I do not want to assume vaccination status, etc.</li> <li>• I will forward the in-person research activities with guidance on sneezing/coughing into a tissue/sleeve, and other hygiene measures.</li> <li>• I have been fully vaccinated against COVID-19 in advance of the fieldwork commencing, and will be sure to take regular lateral flow tests prior to, during and after the allotted fieldwork period. I will also recommend that participants take lateral flow tests prior to the workshops.</li> </ul>

What are the hazards (bold text)/ risks (bullet points)?	What controls have you put in place?
	<ul style="list-style-type: none"> <li>• I will ensure that everybody has the opportunity to use hand sanitiser during the research. Within the sessions, I will also encourage/remind people to to wash their hands at regular intervals.</li> <li>• I will encourage participants to wear face coverings / masks / visors, if they are comfortable and able. I will also provide disposable one-use face masks for people during any in person research activity.</li> <li>• I will ensure that spaces at TIC-Hull in which research takes place will be well ventilated, to further minimise risk</li> <li>• If I test positive following workshops, the participants will be notified via the internal notification system at TIC-Hull via contact emails provided to me at the beginning of the research, in case the track and trace system does not pick this up. This will allow people to isolate appropriately.</li> <li>• If a participant tests positive, I will follow the same procedure.</li> <li>• I will ask people to confirm that they do not have any COVID-19 symptoms by signing a document at the beginning of any in-person research activity, and will remind them in advance not to come if they have symptoms.</li> <li>• I will ask people in advance of the in-person research activities (during the conversation prior to the signing of a consent form) if the individual has any underlying health conditions (including but not restricted to being immunocompromised). If there are people who are classed as clinically vulnerable, I will seek to conduct those aspects of the research online.</li> <li>• Refreshments will be provided in a COVID-safe manner, and will be pre-packaged with allergens displayed (this will also reduce risk of cross-contamination of allergens). I will also recommend that participants bring their own water bottles where possible (there will be options to refill at TIC-Hull) . However, I cannot assume that everybody has one, and so disposable plastic cups will be available also.</li> <li>• This risk assessment will be reviewed in the weeks/days leading up to the research, with control measures being reviewed against specific UK</li> </ul>

What are the hazards (bold text)/ risks (bullet points)?	What controls have you put in place?
	Government guidelines. Any changes will be communicated to all participants.

## Emergency Procedures (You need an emergency plan even if you are undertaking UK based fieldwork)

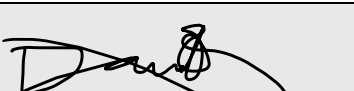
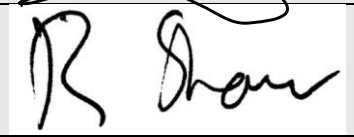
In the case of an emergency, I will contact the emergency services (999) and when safe to do so, I will be sure to contact both my emergency contacts and supervisors.

My emergency contacts will know the location and organisation I am travelling to each time I am on fieldwork. I will text to confirm arrival and departure. If I have not contacted my emergency contact in 2 hours of the expected time, they will contact me. If there is no response after a further hour the police and my supervisors will be contacted. My supervisors and I will have a list of the organisations and the named person I am working with there. They will also be informed of the fieldwork visits. This will be the case for all in-person activities, all of which will occur at TIC-Hull's offices.

My contacts:

Name: Leah Chan  
Relationship: Colleague  
Phone: 07597 254412

# Approval

<b>Assessor</b> (Person who filled out the form) <b>name:</b>	Daniel Jones	Signature:		Date:	
<b>Supervisor name:</b> (Just for PGRs)	Robert Shaw	Signature:		Date:	20-07-21

The completed risk assessment form should be e-mailed to: [gps.safetyofficers@ncl.ac.uk](mailto:gps.safetyofficers@ncl.ac.uk) , to be reviewed.

**d. Semi-structured focus group plan (1 page)**

Focus Group Structure

19:00	Introductions	Go around and say a fact about you  Start recording after introductions  Explain that this group will act in an advisory capacity for the project, so that people are welcome to express their thoughts on the project as a whole, etc.
19:10	Icebreaker Activity	Favourite public spaces/least favourite?  What kinds of times/places do you feel comfortable being in?
19:30	Watch BBC video on 'What Not To Say To People With Tourette's Syndrome'	
19:40	Discussion (generic)	What do you think of the video?
20:00	Thoughts on the Geographies of Impulse Project	Explain the research again, ask people's opinions RE focus
20:25	Draw discussions to a close	Thank everyone, say you'll send a debrief document, or that if people want to say anything extra they're welcome to reach out for an interview!

Some prompting questions:

- How does TS impact you?
- How does TS influence your life?
- What do you think is missing in terms of TS services?
- What is public space to you?
- Why did you want to take part in this research?
- A hard moment/experience in public?
- A funny moment/experience in public?

**e. Semi structured interview plan (1 page)**

Interview Structure (Guide)

- Introduce researcher
- Participant to introduce self
- What are some public spaces you enjoy and why?
- What are some public spaces you dislike and why?
- How do you think TS has impacted the ways you interact with public spaces?
- How do you use online spaces? Do you use social media?
- What do you like / dislike about these online spaces?
- Are you involved in any support groups, online or offline? If so, tell me about them
- Do you feel any pressure to disclose TS to people when you're out and about in public space?
  - o Any spaces in particular?
  - o Certain people (age, gender, etc) you feel the need to disclose more?
  - o Do you use any badges or lanyards to indicate disability?
- Do you have anything else you wish to discuss relating to public space and Tourette Syndrome?
- If you could tell people one thing about Tourette Syndrome, what would it be?

f. Zine workshop participant handout (1 page)

TIC Zine Workshop Activities Print out

**Activity 1: Creative Writing**

1. ***What would you like to tell the world about what it's like to be you (/ have tourettes), that you can't just find out about on the internet?***

You can write, draw, find a photo you have taken, you can respond to this question in any way you like!

2. ***Can you write about or draw a picture showing what it is like for you to experience a public space as a person with tourettes?***

A public space can be anywhere that involves the general public, e.g. physical places like supermarkets, cinemas, but can also be digital spaces like twitter and youtube.

**Activity 2: Collaging**

Using the magazines and other materials, We're going to **create a collage or draw a scene that represents your dream public space or safe space**. Somewhere where you feel like you can be yourself, without fear or judgement.

We're going to think about how you could reimagine a public space so that it suits your needs.

**Starting off points:**

- Think about what types of things you would like to see in your safe space?
- How would you want it to look?
- How does it make you feel?
- How would other people behave or what would they say?
- What would make it feel better or safer for you?

**Activity 3: Zine Making**

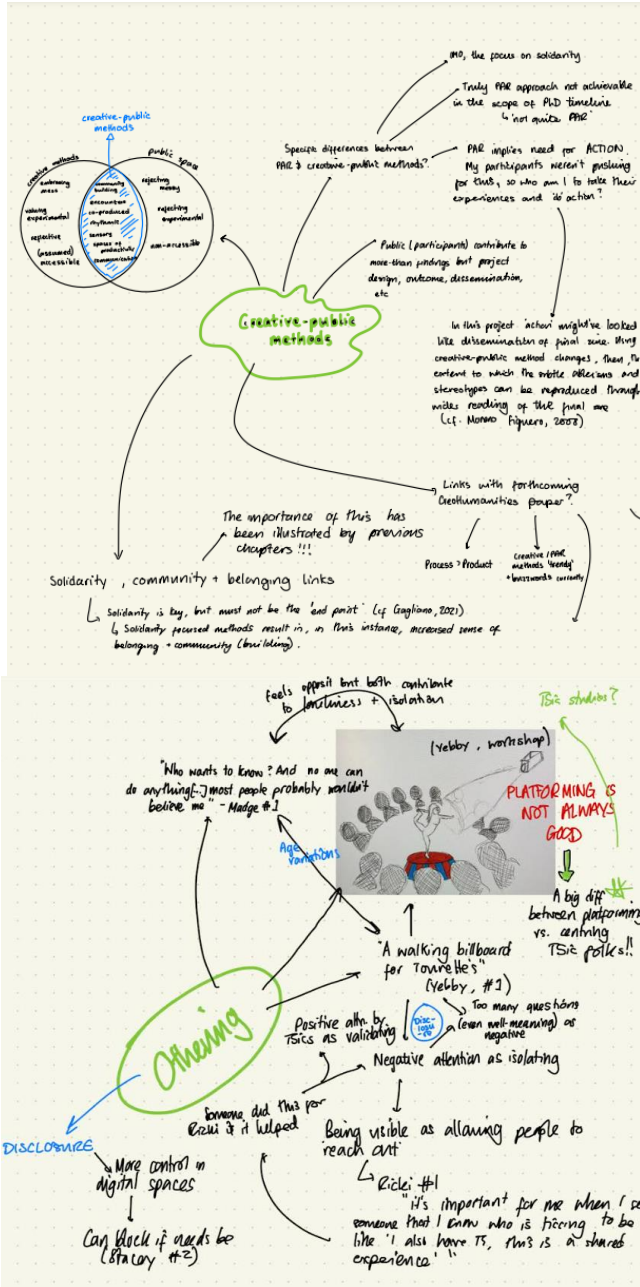
We're going to make some mini zines!

- Any work that you make can be featured in our collaborative zine.
- You might have a theme you already want to explore in your zine, or you could look through the magazines for images or things that stick out to you.
- You could explore your creative writing and collage work further.

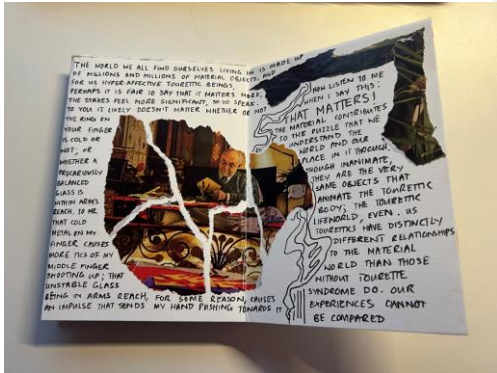
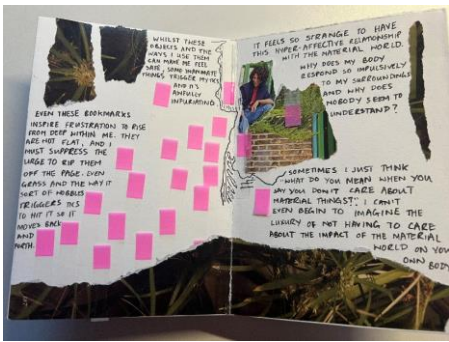
g. Full coding matrix

Main Theme	Sub theme	Sub Theme	Sub Theme
Accessing public space	TS as beneficial	TS as limiting	-
Affect	-	-	-
Age	-	-	-
Anonymity	Positive	Negative	-
Publicity	Positive	Negative	-
Age	-	-	-
Gender	Male	Female	Trans identity
Branding	-	-	-
Hate Crime	-	-	-
Community	Positive	Negative	-
Comorbidity	-	-	-
COVID-19	-	-	-
Disclosure	Symbolic disclosure	Verbal disclosure	-
Faking TS	-	-	-
Disability	-	-	-
Chronic Illness	-	-	-
Neurodiversity	-	-	-
Indicators of social difference	Fidget toys	Stimming Toys	Distraction mechanisms
Disability aids	Mobility	Otherwise	-
Charity	Tourette's Action	TIC-Hull	Tourette Association of America
Intersectionality	Ethnicity	Sexuality	Gender
Isolation	-	-	-
Media portrayal	Positive	Negative	-
Premonitory urge	Suppression of tics	Otherwise	-
Public transport	Positive	Negative	-
Raising awareness	-	-	-
Religion	Christianity	Islam	-
Rhythm	Calm	Chaos	-
Sensory	Under stimulation	Overstimulation	-
Services	Diagnosis	Support groups (digital)	Support groups (physical)
Social media	TikTok	Facebook	Reddit
Stigma	Self	Other	Perceived
Suggestibility	-	-	-

h. Analysis mind map examples



i. Mini-zine example: "Tourette Syndrome and the material world"



**j. Care plan template**

Full name:	
Preferred name:	
Pronouns:	
Allergies and intolerances:	
Any specific accessibility adjustments requested?	
Are there any topics of conversation that you would like a content warning beforehand for?	
Other	