Consensus-based Good Practice Guidelines for the Use of Long-Term Segregation (LTS) with Autistic People: A Delphi Study

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Thesis Abstract

Long-Term Segregation (LTS) is used disproportionately with autistic people in Assessment and Treatment Units (ATUs). Recent investigations into the use of LTS with autistic people have highlighted how often LTS was used primarily due to the main ward environment being unsuitable and distressing for the autistic person, rather than due to the need to manage the risk presented by the patient. There have also been instances of LTS being used in an individualised way with autistic people as a means of providing a more appropriate environment in which to provide care whilst they remain in the ATU. This clinical reality presents a difficulty for Multidisciplinary Team (MDT) staff, as current guidance (i.e. The Mental Health Act Code of Practice 1983) stipulates that the use of LTS must end as soon as possible, with the person being integrated back onto the main ward. However, doing so may reinstate the distress that triggered the use of LTS initially. As such there is an urgent need to develop good practice guidelines that can support the MDT to implement LTS with autistic people in a truly person-centred way which is able to meet the needs of this population whilst minimising the risks of poor care highlighted by recent reports. The current study aimed to produce a set of practice guidelines to inform the good practice of LTS with autistic people.

The Delphi method was used to build consensus through a series of four survey rounds. Participants were 14 MDT members who were either currently working or who had recently worked in ATUs with autistic people in LTS. Prior to the survey rounds an interview asking for three proposed guidelines was completed with each panellist. The round one survey comprised the 41 guidelines generated from the interviews and was sent out to the panel to rate in terms of importance and provide comments. Subsequent rounds were informed by the panels previous round of ratings and comments, with feedback being used to amend and combine guidelines. Consensus was set a priori at 80% or more agreement among panellists that a guideline was essential. This narrow level of consensus was used to make use of the iterative process of the Delphi method in developing and refining the guidelines.

The panel reached consensus that 11 guidelines were essential. These formed the final set and were supplemented by clinical vignettes illustrating the guidelines.

Guidelines were grouped under two broad categories, those relating to direct LTS care, and those relating to the wider service setting around LTS.

The study was limited by the lack of inclusion of family/carer perspectives. The final set of guidelines contained implications for multiple organisational levels related to LTS, from immediate implementation of LTS to wider service factors such as autism training for staff and regular reflective practice specific to LTS. Consequently, effective implementation of the guidelines will require targeting various organisational layers of ATUs to improve the implementation of LTS with autistic people.

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Firstly, I would like to thank Dr Michael Baliousis, who has been a huge support to me through my clinical training and was instrumental in helping me to shape up this study into what it is. I could not have asked for a more patient and encouraging supervisor, not just in the thesis, but in the small-scale research and throughout my second placement in year 2 as my placement supervisor. You helped me contain my frustrations on whilst on training and helped me through the trials of research approval when I was completely lacking patience!

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Statement of contribution

The project was designed and developed by the author in collaboration with Dr Michael Baliousis and Dr Anna Tickle. Both supervisors provided feedback through the research process. They also contributed to the wording of the finalised guidelines and the clinical vignettes, as well as the processes involved in incorporating panellists feedback into the survey rounds, for which the author was chiefly responsible. Dr Michael Baliousis also contributed to participant recruitment.

Dr Jo Varela and Dr Ceri Woodrow provided feedback in the initial planning of the study and writing of the journal introduction.

The author was responsible for applying for and obtaining ethical approval, recruiting participants, conducting the interviews, designing the survey for each round, data analysis and synthesis, and writing up the project.

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Abstract

Purpose

Autistic adults in Assessment and Treatment Units (ATUs) are disproportionately subject to restrictive interventions such as Long-Term Segregation (LTS). No clinically informed guidelines exist to guide staff in effectively caring for autistic people in LTS. As such the purpose of the present study was to produce a set of clinically based guidelines that staff can consult to improve implementation of LTS with autistic people, reduce harms and improve care. 14 Multidisciplinary Team (MDT) members were recruited who had experience in working with autistic people in LTS. The Delphi method was used to build consensus-based good practice guidelines that staff could use to inform their use of LTS with autistic people. Panel members proposed three guidelines and consensus was set at 80% or more agreement across three survey rounds. Consensus was reached on 11 guidelines, 6 related to immediate LTS care, and 5 related to the wider service setting around LTS. Clinical vignettes were created supplementing the guidelines, supporting their application in practice. Some guidelines appeared to reflect aspects of existing guidelines contained in the Mental Health Act Code of Practice 1983, whereas other guidelines elaborated clinical practice recommendations specific to working with autistic people in LTS. The finalised guidelines provide an important resource for staff to implement LTS with autistic people in a clinically informed way specific to the needs of autistic people. Future research should focus on evaluating the utility of the guidelines in practice and explore staff, autistic people, and their family members/carers views of the guidelines.

Keywords: Long-Term Segregation; autism; good practice; Delphi Study; guidelines; clinical practice guidelines

Statements and Declarations

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Introduction

In March 2023, 2,060 people with intellectual disabilities were in inpatient settings in England, 1,320 (64%) of whom were autistic[4] (NHS Digital, 2023), an increase of 26% from 2015 (National Autistic Society, 2023)[5][6]. Alongside rising figures, increasing concerns have been raised about the quality of care offered to this population, and questions asked about the adequacy of inpatient settings to meet their needs (Quinn et al., 2023; Bubb, 2014). The history of systemic abuse and poor care that autistic people and people with intellectual disabilities have received, in settings such as Winterbourne View, Wholrton Hall, and Cawson Park, justify these concerns (Norfolk Safeguarding Adults Board, 2021; Richards, 2020; Triggle, 2019; Care Quality Commission [CQC], 2011).[7] Whilst there are still times when increased risk and levels of distress necessitate inpatient admission (NHS, 2017), these concerns highlight the need to consider how services implement the most effective treatment possible (Melvin et al., 2022).

Assessment and Treatment Units (ATUs) are typically the setting where people with intellectual disabilities are placed when inpatient care is required, offering short-term secure placements following crisis in the community (Learning Disability Today, 2023). As autism has significant overlap with learning disabilities, with 20-30% of people with intellectual disabilities being autistic (Burrows et al., 2023; Emerson & Baines, 2010) autistic people are therefore likely to be supported in ATUs (Jones et al., 2021). Moreover, given the increasing numbers of autistic people being admitted to inpatient settings (NHS Digital, 2023), autistic people are overrepresented in inpatient intellectual disability populations. This presents challenges in delivering quality care for autistic people who, as discussed below, have distinct needs that ATUs struggle to meet, contributing to concerns around how inpatient care, when it cannot be avoided under current service provision, can best meet the needs of this population. A particular concern surrounding inpatient care of autistic people is the use of restrictive interventions such as Long-Term Segregation (LTS), which is often implemented with autistic people because the main ward environment is inappropriate (Joyce et al., 2021).

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[4] Many "Autistic people" prefer the use of identity-first language (i.e. "Autistic people/person") over person first language (i.e. people/person with Autism) (Ferrigon & Tucker, 2019). As such, this project will used the preferred terminology.

[5] See extended 1.1

[6] See extended 1.5

[7] See extended 1.2

Autism and the Psychiatric Inpatient Context

Autism is characterised by differences in reciprocal social interaction and communication patterns, and restricted, repetitive interests and activities (American Psychiatric Association, 2013). Autistic people may also experience a range of sensory sensitivities and difficulties in integrating sensory information (Lord et al., 2020; Lai et al., 2020; Robertson & Baron-Cohen, 2017). These differences can be challenging in strange social situations that may increase anxiety (Andreou & Skrimpa, 2020), and autistic people may experience increased adjustment difficulties when needing hospital admission, in addition to the distress initially warranting admission.[8]

Few studies focus on the experiences of autistic people in inpatient settings, but existing research suggests that such environments can be particularly distressing.[9] For autistic people, the structure of the inpatient environment can prevent the re-establishment of familiar routines, increasing distress. Other features, such as sensory features like bright lights, cleaning product smells, food textures and the general noise of ward environments without access to quiet spaces can be distressing (Maloret & Scott, 2017; Murphy & Mullins, 2017). Furthermore, reasonable adjustments may not be made, preventing people from engaging in regulatory activities such as pacing, again increasing distress (Limbachya, 2020). Therefore, the restrictive nature of inpatient environments, coupled with inadequate understanding/accommodation to the needs of autistic people, creates an environment that exacerbates distress.

Increased distress may increase the use of restrictive interventions[10], as regulatory behaviour may be perceived by staff as disruptive or may pose a risk to the patient and/or others. Engaging in “behaviours that challenge” may increase for autistic people who struggle to communicate distress verbally (Murphy et al., 2005; Holden & Gitlesen, 2006). Consequently, restrictive interventions such as LTS may be used disproportionately with autistic people (Jones et al., 2021), as indicated by the disproportionate number of autistic people in LTS highlighted by the Care Quality Commission ([CQC], 2020).

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[8] See extended 1.6

[9] See extended 1.6.2

[10] See extended 1.3

Long-Term Segregation

LTS[11] prevents a patient from freely mixing with patients on the main ward, to reduce the risk of harm posed to others (Department of Health [DoH], 2015). Existing guidance (i.e. the Mental Health Act [MHA] Code of Practice 1983) states that LTS should always end as soon as possible, with the person being re-integrated back onto the ward (DoH, 2015). This assumes that communal areas are appropriate for all patients regardless of their needs without considering the difficulties that the inpatient context creates for autistic people. At the same time, the use of LTS to meet the unique needs of some autistic people has been far from an ideal solution. The use of LTS has been criticized[12] due to concerns about human rights abuses of autistic people and people with intellectual disabilities subject to inadequate care in the context of LTS (Joyce et al., 2021; Willis, 2020; Gaskin et al., 2013). Recently, a review examining the use of LTS with autistic people and people with intellectual disabilities identified the disproportionate use of and poor care in the context of using LTS (CQC, 2020). Furthermore, the review also noted how often LTS was used with autistic people because the main ward environment was distressing, rather than any risk posed by the person to others (Joyce et al., 2021). The review also highlighted poor care including lack of involvement of family when implementing LTS, and lack of adequate staff training leading to increase use of restrictive interventions (CQC, 2020).

A limiting factor in the effort to identify a more appropriate environment to support an autistic person in ATUs is that using LTS as a more appropriate environment[13] is not specified in existing national guidance (DoH, 2015), which restricts the use of LTS to minimising risk. The CQC Brief Guide (2020), attempts to provide guidance for using LTS for reasons other than the management of risk, but it is inadequate for staff to effectively implement LTS in an informed way with autistic people. Staff are therefore placed in a difficult situation for which appropriate space in which to support autistic patients and guidance about how best to use existing space is lacking.[14]Importantly, the CQC report highlighted isolated examples of good practice in using LTS, such as more individualised use of LTS to support an autistic person (CQC, 2020).

The policy-practice gap that staff encounter can be understood in terms of Dejours' (2003, as cited in Dashtipour & Vidaillet, 2017) psychodynamic theory of work. This theory delineates

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[11] See extended 1.4

[12] See extended 1.4.1

[13] See extended 1.4.2

[14] See extended 1.7

a fundamental dichotomy between the “prescriptive”—official guidelines like the CQC Brief Guide and the Mental Health Act Code of Practice, which are often detached and inflexible—and the “real”—the actual, dynamic conditions of inpatient care. These prescriptive aspects fail to accommodate the unique challenges posed by autistic patients, such as sensory overload and the need for structured environments, which are often disrupted by the ward environment. Dejours (2003) highlights how the "real" work environment includes unforeseen events and contradictions that staff must address, which the prescriptive guidelines inadequately prepare them for (Dejours & Deranty, 2010).

To respond effectively to the “real” of work, staff must mobilise their intelligence and affect (emotional intelligence, creativity); in the LTS context, this may mean thinking creatively (and compassionately) about using LTS in nonprescribed ways, to create a good enough caring environment for an autistic person. This ultimately requires therapeutic responses incompatible with the prescriptions (Dashtipour & Vidaillet, 2017), such as not implementing the rule of ending LTS as soon as possible. However, prescriptions within national or local policy may make it difficult to implement such changes consistently, which may reinforce the discrepancy between the prescriptions and the “real”. This in turn may increase poor care of autistic people in ATU/LTS settings, by for example implementing LTS prescriptively in an overly restrictive way. This view may help understand the increased reports of the dehumanisation and violation of the human rights of autistic people in inpatient settings (CQC, 2020)

Dejours (Dejours & Deranty, 2010; Dejours, 2003) argues that preventing staff from utilising their professional judgement and empathy leads to a form of ethical suffering, where workers feel disconnected from their ability to perform 'good work'—in this context, providing effective and compassionate care. This misalignment may lead to increased psychological defence mechanisms among staff, reducing their responsiveness and empathy towards patients (Reeves & Sinnicks, 2023; Dashtipour & Vidaillet, 2017). Dejours (Dejours & Deranty, 2010) suggests that an antidote to the prescription/real gap and ethical suffering is enabling workers to engage in collective discussion that enables workers to redefine workplace norms collaboratively to realign guidelines with the complex realities of clinical practice (Smith, 2013).

Clinical Psychologists[15] are well placed to address the lack of informed guidance for effectively implementing LTS with autistic people, as a key part of their role is supporting the development of therapeutic, psychologically informed environments (PIElink, 2019). Creating a more psychologically informed environment involves attempting to consciously use the features of a managed environment (e.g. LTS in ATUs) in such a way as to increase the opportunities to meet the psychological and emotional needs of patients in those environments (Johnson & Haigh, 2010). One way of creating a more psychologically informed environment is to develop psychologically informed good practice guidelines that staff can use to guide their practice and bridge the gap between prescriptions and the realities of trying to provide effective care (Dashtipour & Vidaillet, 2017) for autistic people in ATUs. Consensus building methodologies such as the Delphi method (Barrett & Heale, 2020) may be one way to facilitate the process of bridging the policy/practice, prescriptions/real gap, by bring together a group of individuals in different locations who face similar challenges in caring for autistic people in LTS.

To address the policy-practice gap about the use of LTS with autistic people, the present study aimed to produce clinically based, good practice guidelines staff can use to implement LTS with autistic people to ensure least harm to autistic people whilst in ATUs and improved quality of care. The production of the guidelines was informed by the concept of “mindlines” (Gabbay & Le May, 2004)[16], “tacit guidelines” that form through clinical experience and are developed through interactions with colleagues, rather than through consulting explicit guidelines exclusively (Gabbay & Le May, 2004). As such the study aimed to harness the clinical reality of mindlines by facilitating communication between a group of experts. As such the study adopted a practice-based evidence approach.[17]

Method

Procedure

The Delphi method (Barret & Heale, 2020) was utilised as it was considered superior to other consensus building methods like Nominal Group Technique (NGT; Jones & Hunter, 1995), which can be biased by group dynamics (Vander Laenen, 2015)[18]. The Delphi method provides an anonymous, flexible, and reliable[19] methodology that can be employed remotely,

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[15] See extended 1.8
[16] See extended 1.10
[17] See extended 1.9
[18] See extended 2.1
[19] See extended 2.3

meaning that panellists can be recruited from a wide geographical area. The Delphi approach has also been found effective for developing clinical practice guidelines (e.g. English et al., 2020). Quality criteria were applied to strengthen the validity of the study (Diamond et al., 2014).[20] The Delphi method was also chosen as an effective method for harnessing the reality of mindlines (Gabbay & Le May, 2004), through the use of relevant experts forming the Delphi panel and providing their clinically informed recommendations to develop the guidelines, based on their clinical experiences.

All participants signed online consent forms before participating in the study, and ethical approval was obtained from the University of Nottingham Health Research Authority Research Ethics Committee (Reference number: 22041).

Study design

The "classic" Delphi method[21] was followed (Thangaratinam & Redman, 2005), utilising three survey rounds and a fourth round for eliciting panellist feedback on the final guidelines.[22] Participant interviews were completed prior to the survey rounds to elicit proposed guidelines and clinical examples for vignettes.

Interview schedules[23] were designed in consultation with the research team. Interview questions explored panellists' experiences of using LTS with autistic people. Interviews also elicited examples of using LTS with autistic people, examples of LTS being beneficial and times when LTS usage has not gone well. Probing for examples enabled the guidelines to be more specific and based on recollections of concrete clinical experiences (Robinson, 2023). Panellists were then asked to provide three proposed guidelines that would form the anonymous survey.

Consensus[24] was set a priori at 80% or more of responses falling in the highest or lowest Likert Scale options.

Participants and Recruitment

In line with recommendations in the Delphi literature (Turoff & Linstone, 2002), participants[25] were recruited via snowball sampling (Goodman, 1961) through professional networks of clinicians working in the context of ATUs across England, local ATU

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[20] See extended 2.11

[21] See extended 2.2

[22] See extended 2.4

[23] See extended 2.5

[24] See extended 2.9

[25] See extended 2.6

Psychologists and Psychiatrists, and social media. The Restraint Reduction Network and The Challenging Behaviour Foundation were contacted with emphasis in relation to inviting parents/carers. The study generated a sample of MDT members from a range of professions and from a range of working contexts. However, the study did not successfully recruit any parents/carers. Participants were referred to as "panellists" as they each individually contributed to consensus building through their responses (Rowe & Wright, 1999). The study aimed to recruit two of each MDT member listed below, and two parents and/or carers.

The research team considered the inclusion of autistic service users (i.e. autistic people who have experience of being in LTS) on the panel. After careful consideration it was decided not to include service users in the study. This was related to the legal aspects of LTS and the technical aspects of the Delphi process.

Inclusion Criteria

MDT members were required to have one year's clinical experience minimum in a role that included working with autistic people and people with intellectual disabilities in ATUs. One year's clinical experience was deemed the minimal amount necessary to be able to offer practice-based examples and proposed guidelines. MDT members (as per the inclusion criteria) included Psychiatrists, Clinical Psychologists, Speech and Language Therapists, Physiotherapists, Occupational Therapists, Ward Managers, Nurses, Clinical Nurse Specialists, Healthcare Assistants, and Advocates who have experience caring for autistic people who are of have been in LTS. Parents/carers could participate if the autistic person they cared for had been in LTS in the last year.

Exclusion Criteria

Participants were excluded if experiences of LTS were confined to forensic inpatient units, due to that context and patient population being different compared to ATU contexts and populations. Participants were also excluded if they resided in any other country apart from England, due to legal differences compared to England.

Interview Round

BG completed interviews with panellists using Microsoft Teams. The aim and purpose of the study was clarified with panellists, who were reminded of the definition of LTS as set out in the MHA Code of Practice 1983 (DoH, 2015) at the start of the interview. The purpose of the interviews was to explore panellist's experiences of the use of LTS with autistic people as a means of warming the context for then asking participants to provide three proposed guidelines at the end of the interview, based on their clinical experiences. Exploration of examples of clinical practice also provided content for the clinical vignettes that supplemented the final guidelines. All clinical vignettes were anonymised to protect confidentiality. At the end of interviews proposed guidelines were elicited from panellists and transcribed verbatim for the survey, being amended only to correct grammatical errors and otherwise not analysed, to preserve the validity of the Delphi process (Okoli & Pawlowski, 2004). Once all guidelines were collected, they were collated into conceptual categories by the research team, to improve accessibility (e.g. English et al., 2021).

Round 1 Survey

Once the proposed guidelines were collated and organised, surveys were sent to panellists via email, who were asked to rate the guidelines in terms of importance on a five-point Likert Scale (1 = not important at all, 2 = not very important, 3 = neutral, 4 = important, 5 = essential). Space was also provided for comments on ratings or anything else panellists wish to share. Participants had two weeks to complete the survey. Reminder emails were sent halfway through the round, two days before the deadline and on deadline day. If panellists did not return the completed survey after two weeks, a further five working days were allowed to complete the survey.

Round 2 Survey

Percentage agreements on survey items were calculated from Round 1. Personalised surveys were produced presenting how each panellist had responded in Round 1. Individual responses were set alongside the overall panel response, with percentages being displayed below each point (see Figure 1). Comments were also presented in anonymised format below corresponding guidelines. Guidelines reaching consensus to be included were presented at the top of each section (i.e. Direct LTS Care and Wider Service Setting sections) and highlighted in green. Significantly modified guidelines were included for re-rating. Guidelines requiring re-rating were presented in original order from Round 1, with numbering retained. Some guidelines received minor amendments prior to circulating based on panellist comments. These amendments were indicated using italics. For guidelines[26] that were significantly reworded, the original was presented for rating and an alternative guideline presented below, with panellists asked to indicate if they wanted the new version to replace the original guideline. These amendments were made when two or more panellists made similar

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[26] See extended 2.7

comments/suggestions. Two weeks were given to complete the survey, with the same arrangements as the previous round.

Figure 1. *Example of item from round two survey*

<table>
<tr><td colspan="6">7. Ensuring the use of LTS is individualised to suit their needs. It’s got to fit that individual.</td></tr>
<tr><td></td><td>Not important at all</td><td>Not very important</td><td>Is neither unimportant nor important</td><td>Is important</td><td>Is essential</td></tr>
<tr><td>How the panel answered the round 1</td><td></td><td></td><td></td><td>31%</td><td>69%</td></tr>
<tr><td>How you answered in round 1</td><td></td><td></td><td></td><td></td><td>X</td></tr>
<tr><td>New response</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="6">Comments other made:
• I would like to say that this is essential, but realistically there is very limited flexibility in the setup of LTS space, without additional funding resources. However, creative working across the team and with the patient and their triangle of care can make spaces more bespoke and successful.
• Changing with patient as their need’s changes so therefore flexible and not set in stone.
• This is a must.</td></tr>
</table>

- Yes, but this is quite vague. We need to be clear what we are actually advising here.
- May be cost implications which can’t always be done quickly and typically it is a last resort, urgent decision.
- Applies equally in and out of LTS.
- This should always be an ongoing process and acceptance of the fact this may be changeable following ongoing risk assessment.

Round 3 Survey

Round 3 survey was formatted and administered identically to Round 2. Guidelines that were voted to be removed or to be replaced with an alternative guideline were retained in the survey to maintain transparency and highlighted in grey. Guidelines approaching consensus were highlighted in orange. Panellist comments were incorporated when two or more panellists made similar comments/suggestions. The panel was also asked specific questions to clarify the meaning of certain guidelines.[27],[28]

Round 4 Survey-Finalised Guidelines

Panellists were asked to member check (Birt et al., 2016) the guidelines that had reached consensus to be included. Member checking refers to the method of returning data to participants to verify the quality of the data (Birt et al., 2016). Clinical vignettes were also shared alongside their corresponding guidelines for review. Vignettes were derived by the primary researcher from interview transcripts and anonymised. The guidelines and vignettes were reviewed by MB and AT before being sent to panellists. Where no appropriate vignettes could be derived, panellists were asked to provide examples.

Panellists were also asked if some guidelines deemed similar by the researchers should be combined. These guidelines were presented alongside combined versions, and panellists were asked to indicate their preference. It was also made clear that no other changes would be made to guidelines in response to feedback provided, unless multiple panellists highlighted similar points.

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[27] See extended 2.8

[28] See extended 3.6

Results

Participants characteristics are shown in Table 1.[29] 17 individuals expressed an interest in participating. Two did not meet inclusion criteria, and another, a parent/carer, did not respond to follow up emails, meaning an interview was not completed. 14 individuals made up the final "expert panel". Attempts to recruit parents/carers were not successful. The panel consisted entirely of MDT members. Relevant experience ranged from one year three months to 33 years, and all panellists had recently, or were currently working in ATUs. Six NHS Trusts were represented in the sample. Figure 2 summarises contributions throughout the Delphi process.

Interview Round

Interviews lasted between 49 and 73 minutes and generated 41 proposed guidelines[30], with each panellist providing three proposed guidelines and one panellist who provided two. The guidelines fell broadly into two categories, "Guidelines immediately related to direct LTS care" (19 guidelines), and "Guidelines relating to wider service context around LTS" (22 guidelines). Guidelines were placed in either category based on similarity of content. Panellists were all able to provide examples of clinical experiences of the use of LTS with autistic people, which they then drew on to propose specific guidelines. See supplementary material for a list of all proposed guidelines.

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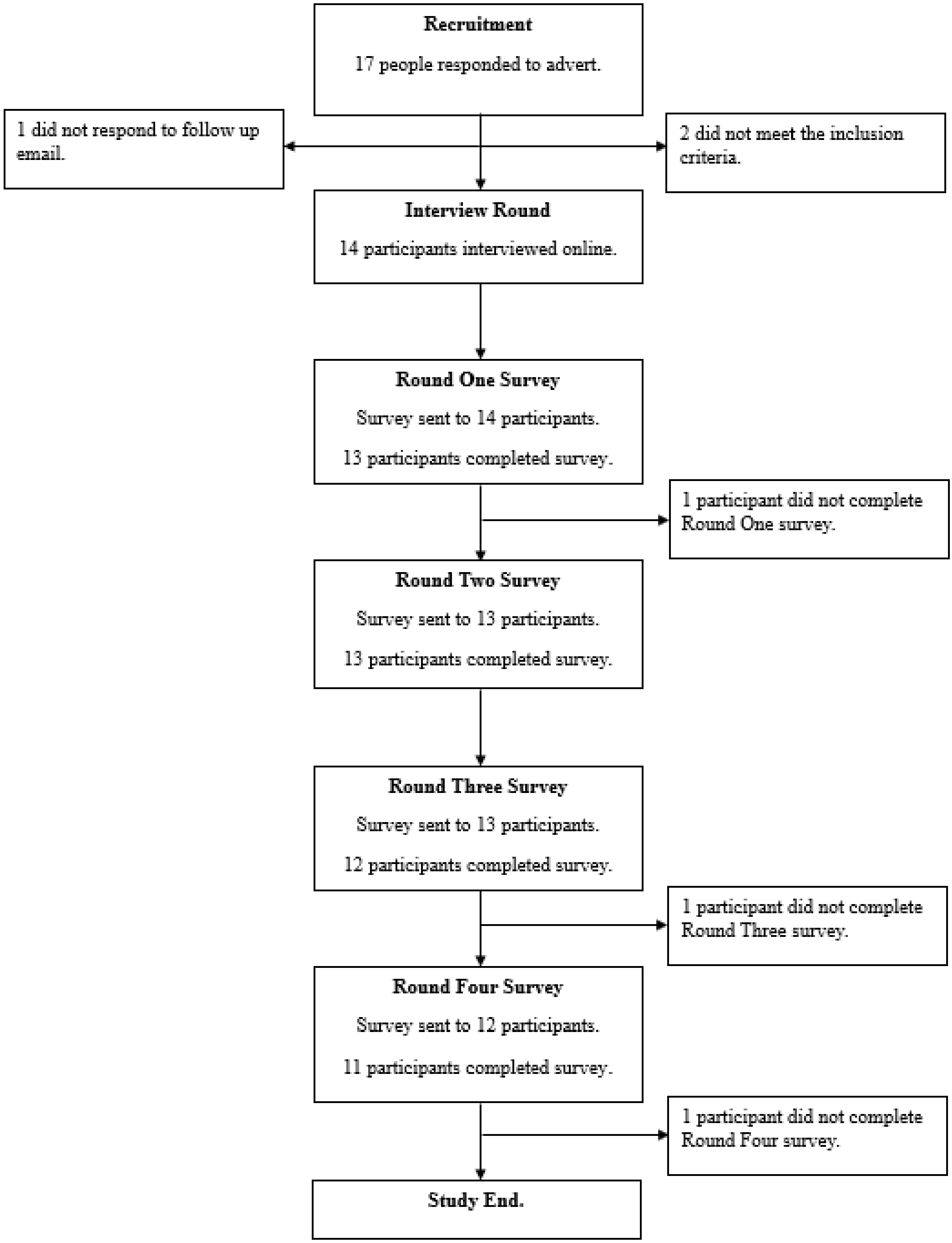
[29] See extended 3.1

[30] See extended 3.2

Table 1. *Expert Panel Demographics*

Years of Clinical Experience in Assessment and Treatment Units		**Professional Role**		**Geographical Location**	
1-9	8	Healthcare Assistant	2	Nottinghamshire	8
10-19	4	Nurse	2	Northwest London	2
20-29	0	Clinical Nurse Specialist	2	Cheshire	1
30-39	1	Occupational Therapist	2	Sussex	1
		Speech and Language Therapist	1	North Staffordshire	1
		Ward Manager	1	Derbyshire	1
		Clinical Psychologist	2		
		Consultant Psychiatrist	2		

Figure 2. Flowchart of participant contributions.



Round One Survey

90% of participants (*N*=13)[31] responded to the Round One Survey and follow up email reminders. Two panellists returned the survey incomplete, with one panellist not rating two items and one panellist not rating one item. All other surveys were returned fully complete. Consensus agreement (80%) was reached on guideline 11 in the Direct LTS Care Guidelines category that it was essential, while four guidelines were "approaching consensus" (70%). For the remaining 36 guidelines there was no consensus. Therefore 40 guidelines required re-rating.

All guidelines received at least three comments[32] and the most commented on guideline (Guideline 10) received 11 comments (*M*=6.80). The number of comments made by panellists ranged from 1 to 41, with all panellists leaving at least one comment. Comments related to expressing disagreement with part of or the entire guideline, general comments that did not express either agreement or disagreement with the guideline, and supportive comments for the guideline. Other comments related to ensuring guidelines were person-centred, lack of specificity to LTS, wording, suggested improvements, issues with clarity or vagueness, overlap with other guidelines, and guidelines already existing in other guidance.

Following panellists' comments as well as observations made by the researchers (i.e. correcting grammatical errors), a total of 17 modifications were made to the guidelines before Round Two. Nine modifications were for minor changes to wording, for example to increase clarity. Four changes were for significant changes to wording of certain guidelines, resulting in alternatively worded guidelines, for rating regarding agreement and whether it should replace the original. Finally, four changes related to significant overlap being identified either by panellists or by the researchers, also resulting in alternative combined guidelines for rating in the same manner.

After adding alternatively worded guidelines and combined guidelines, there was a total of 48 guidelines that required re-rating, and one guideline that had achieved consensus to be included in the final guidelines. The additional seven guidelines were either combined guidelines or alternatively worded guidelines. Panellists were also asked to provide any comments on the structure of the guidelines into the two categories. Two comments were provided that did not directly address the structure of the guidelines.

Round Two Survey

100% of remaining participants completed the Round Two Survey. Five panellists returned surveys with some items having not been rated. Two panellists did not rate one item, one panellist did not rate two items, one panellist did not rate four items, and one panellist did not rate five items. All other surveys were returned fully complete. Consensus agreement was reached on nine guidelines for ratings of essential (Guidelines one, three, six and 18 from the Direct LTS Care Guidelines category, and guidelines four, five, six, seven, and 12 from the Wider Service Setting Around LTS Guidelines category), while nine guidelines were approaching consensus. For the remaining 30 guidelines that required re-rating, there was no consensus. Therefore 39 guidelines needed re-rating.

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[31] See extended 3.3

[32] See extended 3.4

Two guidelines received no comments from panellists, with all others receiving at least one comment, with the most comments for one guideline being five (*M*=2.5) for the alternative combined guideline for guidelines six and 10. The number of comments made by panellists ranged from 0 to 38, with one panellist leaving no comments. Most comments related to uncertainty or disagreement with the whole or part of a guideline. Other frequent comments related to general comments expressing neither agreement or disagreement with a guideline, identifying overlap with other guidelines, wording, and guidelines already existing in other guidance. Other comments related to lack of specificity to LTS, suggested improvements, and comments directly related to other panellists' comments.

Following panellists' comments, a total of 16 modifications were made to the guidelines before Round Three. Eight modifications were made for minor changes to wording, three changes were for significant changes to wording, and five changes related to combining guideline where overlap was identified. All changes were indicated to panellists as they were indicated in Round One.

After adding alternatively worded or combined guidelines, 47 guidelines required re-rating. Of these 47, 14 did not require re-rating as they had been voted to be replaced with either an alternatively worded guideline or an alternative combined guideline. As such 33 guidelines required re-rating in Round Three.

Round Three Survey

90% of remaining participants (*N*=12) completed the Round Three Survey. Seven panellists returned surveys with some items having not being rated. Two panellists did not rate two items, one panellist did not rate one item, one panellist did not rate four items, one panellist did not rate five items, one panellist did not rate eight items, and one panellist did not rate 13 items. Consensus was reached on five guidelines for ratings of essential (alternative combined guideline for guidelines 12 and 13, alternatively worded guideline 17, and alternatively worded guideline 19 from the Direct LTS Care category, and alternative combined guideline for guidelines two, three, and four, and alternative combined guideline for guidelines 17, 18, and 19 from the Wider Service Setting category), while nine guidelines were approaching consensus. For the 21 remaining guidelines that required re-rating, there was no consensus.

Six guidelines received no comments from panellists, with all others receiving at least one comment, with the most comments for one guideline being five (*M*=2.8). The number of comments made by panellists ranged from 0 to 27 with one panellist leaving no comments. Comments related to wording, uncertainty, or disagreement with whole or part of a guideline, and guidelines lacking clarity or being vague. Other less frequent comments related to identifying overlap with other guidelines, ensuring guideline is person-centred, and lacking specificity to LTS.

Round Four – Finalised guidelines with clinical vignettes

At the end of Round Three, 14 guidelines had reached consensus to be included in the final guidelines from across all three survey rounds. Of these, three pairs of guidelines were identified as similar by the researchers[33], with alternative guidelines that combined the two similar guidelines presented to panellist for their consideration (see Method). All three

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[33] See extended 3.5

alternative combined guidelines were accepted by the panellists, replacing the original guidelines, leaving a total final set of 11 guidelines (See Table 2). In the final round panellists were also asked to check the guidelines, provide comments, and provide examples of clinical vignettes illustrating the guideline where necessary.

90% of the remaining participants completed the final Round Four Survey (*N*=11). Panellists provided at least two comments on each aspect of the guidelines (introduction and each guideline) that were requested, with the most comments for a single aspect being eight comments (*M*=4.3). The number of comments made by panellists ranged from 3 to 28, with most comments being supportive comments for the guidelines, and general comments about the guidelines expressing neither agreement nor disagreement. Less frequent comments related to wording and uncertainty or disagreement with the whole or part of a guideline. Panellists provided a total of 19 examples of clinical vignettes in this round. Of these, three were incorporated into the finalised guidelines. 10 more clinical vignettes were derived from the interviews completed with panellists in the Interview Round, and three other clinical vignettes were provided by the wider research team to ensure all guidelines had at least one clinical vignette that illustrated the guideline.

After Round Four the panellists were sent the finalised guidelines and clinical vignettes, and informal feedback was received from three panellists who provided positive feedback on the guidelines. One person's positive feedback reflected that the guidelines in their final form will be helpful in improving the way that LTS can be used with autistic people and that the clinical vignettes help to illustrate the guidelines.

Table 2. Endorsed guidelines and their level of consensus (consensus percentages rounded to whole numbers).

Category	No.	Guideline	Modifications (none, minor, major, combined)	Level of consensus
Direct LTS Care	1.	A graded step-by-step plan of how we support someone out, to reduce the risk of someone just living in LTS, and that becoming the new status quo.	None	92%
	2.	Ensure a stimulating and engaging environment is maintained that meets the person's needs, but it is tailored individually, wherever possible. This can be informed by multidisciplinary team assessments.	Two guidelines combined from Round Three	Both original guidelines (guidelines three and four) achieved at least 80% consensus (85% and 91% respectively) before being

				combined in Round Four.
	3.	Ensure that communication is tailored to the persons communication needs both in terms of: 1. Communicating with the person generally when they are in LTS. 2. Communicating the process of LTS to the person in terms of starting, going through, and ending LTS. This can include communicating the reasons for using LTS, how the team are going to support the person in LTS, and what role the person themselves can play in the process. Communication may also include information about how the person may be supported to return to the main ward, where this is an appropriate option for the person (given their needs).	Two guidelines Combined from Round Three	Both original guidelines (guidelines 11 and alternatively combined guideline 12 & 13) achieved at least 80% consensus (92% and 90% respectively) before being combined in Round Four.
	4.	Ensure a robust formulation is developed relating to why LTS is beneficial for the person, including whether LTS is the least restrictive and most appropriate option for this individual. It should include a clear idea of what it would be like to end LTS (if this is appropriate for the person). The formulation should also include a "Moving Forward Plan" that details how the person can be supported to be safely discharged. Reviews should focus on whether LTS is working for the person and what needs to happen next.	Three guidelines combined from Round Two	100%
	5.	Maintain the engagement of the person and build a trusting relationship with them when they are	Two guidelines combined	Both original guidelines

		in LTS. This process should consider the potential negative impact of the use of LTS when building a relationship with the person. Factors that have impacted on the person’s ability to form trusting relationships should also be considered. These include attachment processes, and how problems such as fear, uncertainty, mistrust, and being separated from others when in LTS, may impact the relationship with the person when in LTS.	from Round Three	(guidelines 17 and 19) achieved at least 80% consensus (92% and 90% respectively) before being combined in Round Four.
	6.	Value the person. Treat them with respect, give them choices wherever possible and appropriate for the individual (i.e. making choice facilitation person-centred). That can be overlooked when choices end up being made for them. Just a simple choice like “Do you want ice-cream, or do you want jelly?” could mean so much and can be so validating to somebody.	Minor	92%
Wider Service Setting Around LTS	1.	Involve staff in the development of the LTS and stepdown plan, so right at the onset, they know what is expected. Staff on the ground, healthcare assistants (HCAs) and support workers.	None	92%
	2.	Ensure the use of LTS is fully staffed. For it to be successful you need to make sure you have a shift that is fully staffed. If a shift has the correct staffing levels, the stages of the step-down plan can be implemented. Therapeutically, activities are going to take place. Positive interactions are going to take place.	Minor	85%
	3.	Involve the family. Keep them up to date. Be open and transparent where things are difficult and admit to that when encountering problems. Have family input into staff’s understanding of the person, for example discussing the family's understanding how the person likes to be engaged and modelling this in	Minor	92%

	their care where possible. All family involvement must be considered in light of potential safeguarding history in relation to family members and the person's consent for family to be involved where this is possible.		
4.	Train staff on autism specifically, but then ensure there are reflective spaces to support staff to continue with that reflection on training afterwards.	Minor	85%
5.	Regular reflective practice specific to LTS that includes all MDT members involved in LTS, including healthcare assistants (HCAs). Discussions should cover issues specific to LTS, including restrictive practice, barriers to change, and whether LTS remains appropriate for the person being cared for in LTS. Reflective practice should help staff to maintain their moral agency and enable them to speak freely and openly, as well as mitigating against burnout, trauma and moral injury.	None	83%

Note. LTS: Long-Term Segregation; HCA: Healthcare Assistant; None: guideline remained in original form; Minor: grammatical changes that do not change the overall meaning of the guideline; Major: substantial changes to wording that alter the meaning or emphasis of the guideline; Combined: a new guideline formed through combining to existing guidelines into one.

Discussion

The present study aimed to draw on the experiences of MDT staff and parents/carers, to develop a set of clinically based, good practice guidelines that MDT staff could draw upon to effectively implement LTS with autistic people in ATUs. Eleven guidelines (six related to direct LTS care, five related to the wider service setting around LTS) were endorsed by the panel at the end of the consensus building process.

Direct LTS care guidelines

The six direct LTS care guidelines touched upon areas such as ensuring a graded, step-by-step plan is in place to bring the autistic person out of LTS; ensuring that the LTS environment is engaging and tailored to the individual; communicating effectively to the person about the rationale for and process of LTS; ensuring that a formulation of why LTS is appropriate is in place; maintaining engagement and building trusting relationships with people when in LTS; and valuing the person and treating them with respect.

Regarding Direct LTS Care guideline one (See Table 2), recent reviews (CQC, 2020) and research (Joyce et al., 2021; Richardson et al., 2020; Webber et al., 2014) have highlighted the disproportionate use of restrictive interventions such as LTS specifically with autistic people, as well as highlighting how often, patients did not have plans to be re-integrated back onto the ward (CQC, 2020). Furthermore, the MHA Code of Practice 1983 states that care plans should include the aim of ending LTS and re-integrating the person back onto the main ward. As such, by endorsing Direct LTS Care guideline one, the panel appeared to privilege the essence of this aspect of the MHA Code of Practice 1983 (DoH, 2015). Furthermore, the endorsement of this guideline appeared somewhat contradictory. For a similar guideline (which did not reach consensus to be included) which referred to ensuring that staff know that LTS “is not a long-term solution”, multiple panellists commented that in some instances, LTS may be more appropriate for an autistic person’s care than being on the main ward. As such the discrepancy between some of the guidelines endorsed and the panellists’ comments may reflect a tension between clinical judgement and the perceived need to uphold existing guidance. More specifically, the tension could be said to be between two solutions (ward environment vs. LTS), both of which seem far from ideal.

Furthermore, the apparent tension between clinical judgement and formal, legal guidance and requirements reflects a tension between sources of knowledge that constitute “mindlines” (Gabbay & Le May, 2004). Mindlines are said to be built from, among other sources, both tacit and explicit knowledge sources (Gabbay & Le May, 2004). In this context, tacit knowledge (i.e. clinical experience, understanding of individual autistic people's needs), may contradict explicit sources of knowledge (i.e. the MHA Code of Practice 1983) that inform clinical care of autistic people. As such, the tension within the panel in endorsing contradictory guidelines may be reflective of a contradiction within the context of the current care system for autistic people in ATUs. Additionally, this contradiction highlights the discrepancy between work prescriptions (MHA Code of Practice) and the realities of the work (e.g. using LTS in ways responsive to the needs of autistic people; Dejours & Deranty, 2010), and possibly highlights an insufficient sense of collectiveness amongst NHS staff, who may feel pressure to uphold prescriptions over their own clinical judgement.

Other guidelines in the Direct LTS Care category appeared to depart from existing guidance, for example Direct LTS Care guideline two. The MHA Code of Practice 1983 (DoH, 2015) states that LTS should be only as restrictive as necessary and be as "homely and personalised" as risk allows. By endorsing a guideline that places emphasis on the LTS environment being tailored to the individual autistic person, the guideline lines avoid the presumptions contained in terms such as "homely". The term "homely" may imply neurotypical assumptions about what counts as a "homely" environment, but which may not be preferred by some autistic people, who may have their own preferences related to their specific needs as autistic people. This point about the generic term "homely" is contained in another guideline which did not reach consensus for inclusion, but which pointed out that the LTS environment needs to be individually tailored for the person to meet their specific needs. Direct LTS Care guideline two therefore points towards the importance of carefully considering the complexity of the needs of autistic people, such as possible sensory sensitivities and limited range of interests (Lord et al., 2020; Lai et al., 2020; American Psychiatric Association, 2013), and how the environment may impact upon these needs.

Other Direct LTS Care guidelines appeared to elaborate, in more precise detail, aspects that are only briefly touched upon in existing guidance, such as ensuring that there is a formulation that states the rationale for the use of LTS for the individual and ensuring that a trusting and supportive relationship is maintained particularly in the context of LTS. In other respects, the guidelines seem to go beyond what is captured in existing guidance such as the MHA Code of Practice 1983 (DoH, 2015), by for example emphasising the importance of addressing psychological factors such as attachment processes and ensuring that the emotional impact of being placed in LTS is considered (Direct LTS Care guideline five). The finding that some guidelines elaborated in more detail on existing guidance, and even went beyond existing guidance in terms of specificity, reflects Gabbay and Le May's (2004) finding that often, existing clinical guidelines were not detailed enough for clinicians to effectively address the problem, hence necessitating the emergence of "mindlines"; tacit, but much more specific and context-sensitive than any formal guidelines could be.

The final Direct LTS Care guideline (Direct LTS Care guideline six) emphasised the importance of valuing the person, respecting them, and providing choice where possible. It is difficult to ignore the concerning implications of the inclusion of a guideline that stresses the need to value another human being, as its inclusion suggests that valuing people unconditionally is not something that happens as part of basic mental health care when working with autistic people. The emphasis on facilitating choice where possible may also reflect the inherent risk, whenever using restrictive interventions such as LTS, of removing a person's choice entirely (Richards, 2020). Furthermore, the wording of Direct LTS Care guideline six, "valuing" the person, alludes to the Valuing People (2001) agenda, which set out to transform the way that people with intellectual disabilities (20-30% of whom are autistic) are supported in Britain (Burrows et al., 2023; Burton & Kagan, 2006). Within the Valuing People (2001) document, there is acknowledgment of the need for systemic change, stating "We can no longer tolerate services which leave people isolated and marginalised." (DoH, 2001, p.22). As such, could the inclusion of a guideline emphasising the need to value people imply that the Valuing People agenda has failed? It may be that the ATU and LTS contexts create a situation where valuing a person unconditionally is simply not possible when they are being isolated through no fault of their own, through implementing LTS.

Wider Service Setting guidelines

The five guidelines that were endorsed from the Wider Service Setting category[34] included ensuring that all relevant staff, particularly healthcare assistants (HCAs) and Support Workers, are involved in the planning around the use of LTS; ensuring that LTS is fully staffed; ensuring that family are involved where appropriate and kept up to date with the persons care in LTS; providing training for staff on autism specifically; and ensuring regular reflective practice is offered to staff specific to the use of LTS with autistic people.

The inclusion of a guideline that stresses the need to ensure that HCAs and Support Workers are involved in the planning around the use of LTS with autistic people (Wider Service Setting guideline one) may imply challenges in the context of ATUs around team working

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[34] See extended 4.1.1

generally. Indeed, one panellist commented that other MDT members tend to have more input and provide more guidance than HCAs and Support Workers whilst acknowledging that often it is HCAs and Support Workers that are most involved in the day-to-day implementation of LTS with autistic people. Another panellist commented that including HCAs and Support Workers in the process of planning the use of LTS may increase the likelihood that they will engage in "a therapeutic risk-taking strategy" in the context of LTS with an autistic person. As such the endorsement of this guideline may suggest that implementing care plans relating to LTS may be negatively impacted if some staff are left out of the planning process, which in turn may negatively impact the quality of the care autistic people receive in LTS. As such the inclusion of this guideline may also serve to counter the impact of hierarchy and power differentials among MDT staff, which can disproportionately favour some views over others (Rogers et al., 2023).

Another guideline in the Wider Service Setting category relating to staff focused specifically on ensuring that LTS is fully staffed (Wider Service Setting guideline two). The inclusion of this guideline by the panel might reflect ongoing systemic issues that inpatient mental health settings such as ATUs face in terms of staffing, with high turnover and reliance on agency staff who do not know the patients (CQC, 2020). Furthermore, Wider Service Setting guideline two is not autism-specific; it relates to basic provision of resources to implement care adequately, before consideration of and adaptation to the specific needs of autistic people. It seems irrefutable that having adequate staffing levels is anything other than essential, but what the inclusion of this guideline suggests is that even generic care in LTS is not always possible, let alone autism-specific care in LTS.

As such, Wider Service Setting guideline two not only highlights the current staffing crisis in the NHS (Waitzman, 2022), but both Wider Service Setting guidelines one and two highlight several service-related factors that may be impacting upon the care of autistic people in LTS. For example, staff involvement may also include ensuring that staff, including and especially HCAs and Support Workers, are offered regular reflective practice. Recent research involving staff working within intellectual disabilities services found that staff value reflective spaces to increase learning and feel supported (Mehta et al., 2022). Involving staff in formulation meetings for people in LTS may also increase their engagement in the process of care, potentially increasing job satisfaction and reducing staff turnover(Whitton et al., 2016). Furthermore, increased staff involvement may improve the quality of care autistic people are receiving when in LTS (CQC, 2020)

The guideline that recommends the involvement of family (Wider Service Setting guideline three) reflects existing guidance around LTS in the MHA Code of Practice 1983 (DoH, 2015), but goes further in specifying that family should be sought in developing an understanding of the person being cared for in LTS, specifically to inform how staff work with and engage them. This is in contrast to the MHA Code of Practice 1983, which states that the families' views should be "taken into account", whereas the above guideline suggests ensuring a more active involvement of family members to shape how their autistic family member is cared for in LTS. The inclusion of this guideline is made even more important owing to the finding that often, reviews of LTS with autistic people did not involve family members or carers (CQC, 2020).

The final two Wider Service Setting guidelines related to autism-specific training for staff that is followed by reflective practice on the training afterwards (Wider Service Setting guideline four), and regular reflective practice for staff that is specific to LTS (Wider Service Setting guideline five). As such these two guidelines are similar but distinct, and touch on the importance of knowledge of and understanding about autism, how this understanding relates to using LTS, and the need for reflective practice. There was again some discrepancy between the voting of the guideline relating to autism training and panellist comments, with some panellists pointing out that autism training, specifically the Oliver McGowan Training (NHS England, 2022), already exists, whilst another said that autism training should be a basic part of a well-functioning ward. In the context of LTS guidelines specifically, the inclusion of this guideline may imply the need for training that specifically considers the interaction between autism and an intervention such as LTS, that may even explicitly cover the clinical reality that for some autistic people, LTS may constitute a preferable space over that of the main ward environment. The CQC (2020) found that often staff did not have the appropriate training in autism and that existing training was not always bespoke to the service. As such, generic training packages may not be suitable for a niche clinical context such as the one focused on in the present study, and instead training that is tailored to the context of both autistic people and LTS may be more effective.

This last point leads into consideration of the final guideline in the Wider Service Setting category. Just as the previous guideline recommended training that is specific to understanding autism in the context of LTS, so the final guideline recommends ensuring that there is a specific focus within reflective practice groups (RPGs) on autism and LTS. The guideline also explicitly refers to reflective practice as in part, enabling staff to maintain their “moral agency”, as well as protecting against burnout, trauma, and moral injury. The endorsement of this guideline suggests that generally the panel view reflective practice as an important component of good practice specifically in the context of LTS with autistic people. Furthermore, it is highly likely that staff that implement the restrictive practice of LTS with autistic people (and neurotypical individuals) will be at risk of experiencing difficult emotions such as guilt, anger, shame, and hopelessness, as well as feeling that they have transgressed deeply held values and/or beliefs (i.e. moral injury; Kamel et al., 2007; El-Badri & Mellsop; 2008; Webb et al., 2023). As such the inclusion of a guideline emphasising the need not only for RPGs, but RPGs that support the expression of MDT staff to explore their potentially conflicted emotions in the context of using LTS with autistic people, seems very important, particularly as a means of protecting against the emergence of abusive practice (Richards, 2020; Triggle, 2019).

As such it may be important to view the last two Wider Service Setting guidelines together, as training and education on autism on its own may be insufficient to create changes in the actual care of autistic people. This assertion is supported by evidence that education alone is often insufficient in creating behaviour change (Arlinghaus & Johnston, 2017). More recent research has highlighted how staff value reflective spaces for learning and creating changes in ways of working, through reflective practice and case discussions (Mehta et al., 2022). Therefore, autism training for staff may only be effective if it is also supplemented by reflective practice. The other guidelines may also be understood as fundamentally interdependent. For example, having well trained staff may improve relationships with an autistic person’s family, as staff may also be able to impart knowledge and understanding to the family, further increasing the family’s trust and engagement with the service, thereby improving the quality of care for the autistic person.

Finally, the guideline on RPGs links to Dejours’ Psychodynamic theory of work (Dejours & Deranty, 2010; Dejours, 2003). The reference to “moral injury” may be understood in terms of Dejours’ concept of ethical suffering (Dejours, 2003, as cited in Dashtipour & Vidaillet, 2017), which arises when workers feel they have not done a good enough job, or where workers feel they have acted in ways that contradict their moral values (Dashtipour & Vidaillet, 2017). It could be that RPGs can play an important function in increasing the opportunities for staff teams to come together and creatively address the contradictions within the work of caring for autistic people in the LTS context. This may include exploring the teams’ affective responses to their care work, as well as creating collective norms around how best to implement the limited resources (i.e. existing guidelines, LTS) at hand to respond as best they can to the distress of autistic patients. Creating context-specific norms and agreements that more effectively answer the realities of work may enable staff teams to limit the risks of creating poor care experiences for autistic people and limiting the chances of abusive practice (Richards, 2020). Furthermore, it may be especially important for teams to have regular opportunities for reflective practice (via RPGs) in the context of using LTS with autistic people, as the mismatch between the care environment and the needs of autistic people may increase the risk of violations of human rights.

Strengths

One strength of the present study was the low attrition rate across all rounds of the Delphi. In the present study, attrition was very low across all four survey rounds, with attrition remaining consistent at 7% when it occurred, which likely minimised attrition bias in this research. The primary researcher meeting with each panellist to complete the interview may have increased their sense of investment and ownership over the guidelines and built a positive working relationship with the primary researcher (McKenna, 1994). It was clear that panellists were also highly motivated to participate in the research. High motivation may have helped develop nuanced results. A possible limitation of highly motivated participants however is the absence of views of the wider workforce. Another strength was the anonymity of the Delphi method, which may have mitigated against the disproportionate influence of dominant individuals and the influence of hierarchy amongst NHS staff (Rogers et al., 2023; Lilja et al., 2011). Finally, another strength of the present study is the inclusion of the voices of frontline care staff (i.e. HCAs and Nurses), whose views are often overlooked in research on the care of autistic people (Ince et al., 2022).

Limitations

A significant limitation of the present study was the absence of the voices of parents/carers of autistic people who had been in or were in LTS. This absence unfortunately replicates related areas of research, such as debates concerning delayed discharge among people with intellectual disabilities and autistic people, which often excludes or overlooks the voices of family members (Ince et al., 2022). The inclusion of parent and unpaid carer voices may have resulted in a different set of final guidelines. Another limitation concerns the constitution of the included sample. Although the panel was made up of MDT members from six different NHS Trusts, the majority (eight) were recruited from a single Trust. This may have influenced the final guidelines as these eight panellists may have been thinking about their service and LTS context when engaging in the Delphi process. As such the guidelines may overly represent some LTS contexts over others in England, limiting their generalizability.

It could be argued that some of the guidelines lack specificity, which may limit the extent to which they can operationalised and applied in practice (Wells, 2021). Related to this last point, although the primary researcher was clear with the panellists during the interview round about the aim of the study and provided some support in wording the guidelines at the end of the interviews, no specific set of expectations were provided to panellists regarding what the guidelines should be like, to reduce researcher bias and preserve the original wording of proposed guidelines. Although the lack of specificity in some guidelines may make applying them in practice more complicated, the general nature of some guidelines increases their flexibility, potentially enhancing their application across different specific LTS contexts. The clinical vignettes also provide specific contextual examples that may further enhance their application in practice. Finally, another limitation is the focus on working with autistic adults in ATUs in LTS. This necessarily limits the applicability of the guidelines, meaning they may not be as applicable to other contexts, such as forensic and child and adolescent settings.

Clinical implications

By producing a set of guidelines that are specific to caring for autistic people in LTS, the study has decreased the policy-practice gap that exists between current existing guidance and the complex clinical reality of supporting autistic people in ATUs. The guidelines are applicable not only to MDT members working directly with autistic people in LTS, but staff working at other organisational levels. In particular, the guidelines within the Wider Service Setting section encourage staff who consult them to consider the systemic factors that have an influence on the capacity of an MDT to deliver good quality care for autistic people in LTS, such as the extent of the involvement of HCAs in the planning of LTS use, appropriate training, and reflective practice. As such the guidelines provide commissioners with important recommendations on the kinds of support and resources that MDTs are likely to need to offer good care for autistic people in the context of LTS.

The guidelines go further in recommending specific considerations around good practice in using LTS with autistic people than parts of existing guidance (i.e. the MHA Code of Practice 1983). For example, in the guideline recommending regular reflective practice, it explicitly refers to reflective practice that acknowledges burnout and the potential for moral injury. In the guideline on ensuring a stimulating an engaging LTS environment, it is explicit about tailoring the environment to the specific needs of the person, rather than just making the environment "homely", as in the MHA Code of Practice 1983 (DoH, 2015). As such, the guidelines may reflect real-world "mindlines" (Gabbey & Le May, 2004), being derived as they were from practicing MDT members. The guidelines may therefore have a face validity for MDTs that more decontextualised clinical guidelines lack. This "real-world" quality of the guidelines may enhance their clinical application.

Finally, the guidelines may help to improve how LTS is implemented with autistic people, by offering recommendations that encourage critical reflection on how LTS is being implemented by MDTs. By adopting the "mindlines" paradigm (Gabbay & Le May, 2004), it is hoped that the guidelines can function as a prompt to support MDTs to reflect on their own practice of LTS with autistic people, and increase the development of good practice in the use of LTS with autistic people.

Future research

It will be important for future research[35] to evaluate the clinical utility of the guidelines to understand their value for both MDT members and autistic people in LTS. Capturing the views of autistic people and their family members/carers will also be very important in beginning to evaluate the guidelines value in enabling MDTs to utilise LTS with autistic people in a more consistently needs-based, person-centred way, rather than adhering to generic guidelines/clinical practice. To implement the guidelines effectively, staff teams should not focus on whether individual guidelines are being met. Rather, as stated above, the guidelines should be seen as more than the sum of their parts and understood in terms of how they are each connected to one another, when delivering high quality care in LTS. For example, Direct LTS Care guideline two, which specifies meeting a person's needs in an individually tailored manner, directly implies other guidelines also be met, such as ensuring effective communication (Direct LTS Care guideline three), developing a formulation of why LTS is beneficial for a particular person (Direct LTS Care guideline four), and maintaining a trusting relationship and considering how LTS may impact relationships with the team (Direct LTS Care guideline five). As such, meaningful implementation of the guidelines (i.e. implementing them as a whole) is an important future research focus.

It may be beneficial to pilot the guidelines and then elicit the views of both staff and patients on how the guidelines have shaped clinical practice in relation to LTS with autistic people.

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[35] See extended 4.4

Further research could also examine the applicability and scope for adaptation of the guidelines in other similar contexts, such as with children and adolescent autistic people or forensic contexts. Utilising a six to 12 month follow up on any services that have trialled the guidelines could be useful in evaluating feasibility and implementation.[36] Finally, given the lack of specificity in some of the guidelines, another focus for future research will be further refinement of the guidelines in practice.

Conclusions

By consulting with MDT members with current experience of working with autistic people in LTS, the present study has generated guidance towards improving the quality of care autistic people receive in ATUs. The guidance produced highlights the importance of considering the immediate and wider organisational factors together when implementing an intervention such as LTS, so that LTS can be as therapeutic as possible and grounded in a person's needs and human rights, when inpatient admission cannot be avoided. Our study provides an initial direction for clinicians and researchers on how to achieve this consistently, by producing a set of guidelines that address both immediate and wider factors around the implementation of LTS with autistic people.

Word Count: 7,967

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[36] See extended 4.2

Supplementary information

All Proposed Guidelines, Alternatively Worded Guidelines, and Combined Guidelines from Across all Rounds

Guidelines immediately related to direct LTS care

1. **A graded step-by-step plan of how we support someone out, to reduce the risk of someone just living in LTS, and that becoming the new status quo.**

2. **Graded approach to coming out of LTS. Starting off with small changes and thinking about what might be meaningful to the patient. If there are issues like noise or sound, are there any changes that could be made to the environment that would reduce the impact of that without using LTS?**

Round 3 alternative combined guideline (original guidelines 1 and 2).

If bolder changes to a person's LTS are not appropriate, there should be a graded, step-by-step plan of how we support them out, to reduce the risk of someone living in LTS becoming the new status quo. The plan can include starting with small changes that are meaningful to the person. The plan should also include a "barriers to change" checklist, which enables staff to discuss concerns about reducing restrictions, consider possible environmental and/or resource barriers and discuss possible solutions to overcome them.

3. **Ensure a stimulating an engaging environment is maintained, but it's tailored individually.**

4. **You need to make probably more focused plans on what that physical environment will look like if you put them in there. You know, do you need so many personal items? Do you need an OT to do a sensory assessment in relation to that person? Sensory needs and adaptation before they go in. So there is more of a focus on the physical environment itself, not just accepting that it is what it is, and we've put them in there because it's risky and that's how it's staying.**

Round 4 alternative combined guideline (original guidelines 3 and 4).

Ensure a stimulating and engaging environment is maintained *that meets the person's needs*, but it is tailored individually, wherever possible. This can be informed by multidisciplinary team assessments.

5. **LTS always seems so cold. Making the environment more nurturing. It needs to be a bit more therapeutic. It’s got to be therapeutic but safe. Even just calming. The rooms lack warmth. And sometimes it does not adequately respect their dignity.**

Round 2 alternatively worded guideline 5.

Making the environment more nurturing. It has got to be therapeutic but safe, calming, warm, and adequately respect their dignity.

Round 3 amended alternative guideline 5.

Making the environment nurturing. *MDTs and observing staff should ensure that attention is paid to whether the LTS environment can be made* therapeutic but safe, calming, warm, *compassionate, and dignified as possible at every moment of the patient’s LTS.*

6. **Develop a brief accessible overview of the person, including likes and dislikes, what makes them happy and not happy, and what stage of the step-down plan they are on. You have to keep it basic for example “Patient A is happy when they are doing X”. And it must be straight to hand because otherwise it can get lost. Don’t lose this basic information. And making sure the staffing team are not just seeing it as a piece of paper, it’s an important part of the structure of segregation. Primarily you are focusing on keeping that patient happy, doing things that they like doing, and working towards that goal of ending it (LTS), or realistically giving them a good positive day**

7. **Ensuring the use of LTS is individualised to suit their needs. It’s got to fit that individual.**

8. **Personalised care but truly being creative about that personalisation makes it sometimes outside of what you would consider to be normal practice. Truly personalising every element of their experience to make it right for them.**

9. **Making sure there is a good formulation of the person’s needs so the whole support context, including environment, is tailored to those needs. There’s an idea that a homely environment is a meaningful generic concept when I don’t**

think it is, it’s what’s a homely environment for this person? Some people like massive multi-coloured stuff, whereas others like white everything. So, it’s really tapping into the individuals needs and desires that way. Really tapping into the whole context for the person

Round 3 alternative combined guideline (original guidelines 4, 7, 8, and 9).

Make sure there is a good formulation of the persons needs that can inform how the physical environment of LTS is going to be tailored to their needs. For example, what personal items are needed? How can the LTS environment be made homely for the specific individual? This approach should aim to personalise care for the person in LTS so that LTS suits their needs and desires, wherever possible

10. **To produce a document which provides staff information on how to deliver tailored and holistic care for a patient in LTS. This could include recording capacity, recording therapeutic interactions, recording interactions that didn’t benefit the patient or which they reacted negatively towards.**

Round 2 alternative combined guideline (original guidelines 6 and 10).

Alternative guideline based on merging guidelines 6 and 10**:**

Brief, accessible document providing overview of patient in LTS. Includes patient’s likes and dislikes, what makes them happy and unhappy, and what stage of step-down plan they are on. Also includes an ongoing record of positive and negative interactions with patient, to provide staff with understanding of how to interact with patient in a beneficial way. Staffing team must view this document as an important part of the structure of segregation and document should be accessible to patient where possible.

11. **Good communication-making sure you know how that person communicates. Because sometimes you’re behind a door and the only thing you can do with that person is communicate. So, make sure you’re communicating effectively to their needs, not just thinking “Oh yeah they’ll understand that” and they won’t.**

12. **Visual representation for the person, that they can input into about what their pathway out needs to look like.**

13. **Clearer communication and adaptable communication, breaking down the process of LTS in terms of starting it, going through it, and finishing it: 'This**

is what you need to do. This is the period of time. What it looks like on a time timer. And this is the consequence or action. This is what you're going to get from that step'.

Round two alternative combined guideline (original guidelines 12 and 13)

Alternative guideline based on merging guidelines 12 and 13**:**

Clearly communicating the process of the LTS to the patient in terms of starting, going through, and ending LTS. Where communicating the LTS is meaningful and helpful to the patient, it must be communicated in a way that suits the patient's communication needs. Can include communicating about what is expected of the patient, what are the consequences of certain actions, presenting time periods on a time timer (if this is helpful).

Round 3 amended alternative guideline (original alternative combined guideline 12 and 13).

Communicating the process of LTS to the person including starting, going through, and ending LTS. This information must be adapted to the person's communication needs. Communications can include what staff are going to do to support the person when they are in LTS, what the consequences of certain actions are, and presenting time periods on a time timer. Consideration must be given to whether communications of this type of information will benefit the person.

Round 4 alternative combined guideline (original guidelines 11 and Round 2 alternative combined guideline 12 and 13).

Ensuring that communication is tailored to the persons communication needs both in terms of:

3. **Communicating with the person generally when they are in LTS.**

4. **Communicating the process of LTS to the person in terms of starting, going through, and ending LTS. This can include communicating the reasons for using LTS, how the team are going to support the person in LTS, and what role the person themselves can play in the process. Communication may also include information about how the person may be supported to return to the main ward, where this is an appropriate option for the person (given their needs).**

14. **Making sure everyone is involved in how it's begun, so it's a team decision. Making sure everyone is on the same page so there's a plan to get someone to long-term segregation, so it doesn't turn into a messy restraint because then that's putting that room in a traumatic situation and that's not going to be a safe area because you've restrained them in that safe area.**

15. **Make sure there is a clear timeframe of what's going to happen when. So, with the step-down plan, when are we starting the step-down plan? When is the next stage of this step-down plan?**

Round 2 alternatively worded guideline 15

Alternative wording for guideline 15 based on comments**:**

Make sure that a clear timeframe has been communicated to the staff team of what's going to happen when, in cases where a plan has been made and needs to be followed. And that this is revised according to the persons response and needs.

Round 3 amended alternatively worded guideline 15.

Establish a clear, step-by-step plan of what the MDT has agreed should happen and which has been communicated to the staff team, in cases where a plan has been made and needs to be followed. This plan should be shared with the person in LTS whenever possible and should be revised according to the persons response and needs.

16. **Understanding how LTS can be a supportive context and shouldn’t always been seen as a context that should end as soon as possible. Or the end as soon as possible in a hospital, should be the person being provided with an appropriate community placement. But it’s interpreted as the person must mix in the general ward, so I think moving things on from that thinking.**

17. **The importance of engagement and relationship building. Critical nature of being able to form a relationship with someone at that point in their life (in LTS), because that makes a massive difference.**

Round 2 alternatively worded guideline 17.

Alternative wording for guideline 17 based on comments:

Maintain the engagement of the patient and build a trusting relationship with the patient when they are in LTS. This process should consider what has impacted on the person’s ability to form trusting relationships, including attachment processes, and how problems such as fear, uncertainty, and mistrust may impact the relationship with the patient when in LTS.

18. **Valuing the person. Treating them with respect, giving them choices. That can be overlooked and you’re making the choices for them. Just a simple choice like “Do you want ice-cream or do you want jelly?” Just simple choices mean so much. And it can be so validating to somebody.**

19. **An awareness for staff of the impact that the individual can experience by making the decision to use LTS. It doesn’t mean that it is the wrong decision, but you may have to work especially hard when you recognise the negative impact for the individual on the decision you made to initiate long term segregation. Once you're aware of that, then it opens up an opportunity to think about how the person might be feeling, what are the signals that we may be inadvertently showing them and telling them by the initiation of long-term segregation? Therefore, what can we do to address it? What we don’t want to do is reinforce any previous trauma or attachment issues, or feelings of self-worth or disappointment that people have already experienced. We don’t need to think about all of these at the forefront of care on a daily basis. But I think we need to think more carefully about it once we've initiated long-term segregation because of the triggers and because of the signals that we’re inadvertently giving to people simply by saying you're separate, you can't mix.**

Round 2 amended guideline 19.

Awareness of the potential negative impact of the use of LTS, for example as it might relate to previous trauma and attachment difficulties and how patients might make sense of being separated.

Round 4 alternative combined guideline (original guidelines 17 and amended 19).

Maintain the engagement of the person and build a trusting relationship with them when they are in LTS. This process should consider *the potential negative impact of the use of LTS when building a relationship with the person. Factors that have* impacted on the person's ability to form trusting relationships *should also be considered*. *These include* attachment processes, and how problems such as fear, uncertainty, mistrust*, and being separated from others when in LTS,* may impact the relationship with the person when in LTS.

Guidelines relating to wider service context around LTS

1. **Ensure all staff know LTS is a short-term situation and that it's not a long-term solution.**

2. **Robust formulation as to why LTS setup is beneficial for that person. Not because it's going to be easier to manage than on the main unit. What's the aim? What are you looking for? And how do you break it down? Including having a clear idea of what it would be like to stop LTS and how you're going to get there.**

3. **Holding in mind what the purpose of the LTS and the purpose of the admission is. Thinking that this person needs to be discharged eventually. Having a plan about how we are going to get there.**

4. **Being clear about why you're using LTS, but also being clear on whether it is the least restrictive and most appropriate option for that person at that time. And coming back to and reminding yourself of why LTS was started. Is it working? And then thinking about what needs to happen next. A continual review process starting with why we made this decision, what are we looking to achieve. So that's a starting point for each review.**

Round 3 alternative combined guideline (original guidelines 2, 3, and 4).

Ensure a robust formulation is developed relating to why LTS is beneficial for the person, including whether LTS is the least restrictive and most appropriate option for the person. It should include a clear idea of it would be like to end LTS (if this is appropriate for the person). The formulation should also include a "Moving Forward Plan" that details how the person can be supported to be safely discharged. Reviews should focus on whether LTS is working for the person and what needs to happen next.

5. **Staff being involved in the development of the LTS and stepdown plan, so right at the onset, they know what's expected. Staff on the ground, healthcare assistants (HCAs) and support workers. That helps them as well.**

6. **Ensure the use of LTS is fully staffed. For it to be successful you need to make sure you have a shift that is fully staffed. If a shift has the correct staffing levels, the stages of the step-down plan can be implemented. Therapeutically, activities are going to take place. Positive interactions are going to take place.**

7. **The involvement of family. Keeping them up to date. Being open and transparent where things are difficult and being able to admit to that when encountering problems.**

8. **Improving understanding of long-term segregation and its application practically. This can be done with the use of case examples.**

9. **To provide staff training in intensive interaction to benefit patients who reside in LTS. By intensive interaction I mean being able to engage at a holistic level to benefit the person in long-term segregation.**

10. **Staff training on the concept of LTS: what it is, why it is used, what are we looking for here, what is the aim? That needs to be more widely incorporated.**

Round 3 alternative combined guideline (original guidelines 8 and 10).

Improving understanding of LTS through staff training on the concept of LTS and its application in practice. LTS training should cover what LTS is; why LTS is used; what the aim of LTS is etc. This training can be complemented using case examples.

11. **Cultural re-education: ensure that staff teams are aware of the autism, but also awareness of its presentation. So that they don't fall into standardised neurotypical practices.**

12. **The training of staff on autism specifically, but then ensuring there are reflective spaces to support staff to continue with that reflection on training afterwards.**

Round 3 alternative combined guideline (original guidelines 11 and 12).

Cultural re-education focused on training staff about autism specifically with an awareness of how autism can present. An aim of this training would be to prevent staff falling into standardised neurotypical practices. Reflective spaces should also be provided for staff to reflect on the training afterwards.

13. **Regular reviews, dynamic risk assessment, and evaluating the risk management plan and regularly updating it. When the risk is deemed significantly reduced in terms of risk to others, looking at bringing the person out. Getting staff to manage the other patients. Agreeing with the MDT at which point. Finding the appropriate time. Putting a plan together.**

14. **Really robust review: processes that enable ATUs to support each other to complete robust reviews of people in LTS. Seeking a second opinion that challenges the decisions we have made.**

15. **Regular review in the team and having Commissioners coming into regular ward rounds and CPAs, as they have local knowledge as well as authority to commission services.**

Round 2 alternative combined guideline (Original guidelines 13, 14, and 15)

Alternative guideline based on merging guidelines 13, 14, and 15:

Ensure that reviews of LTS are completed regularly that involve the contribution of commissioners wherever possible as they have local knowledge. Reviews should include evaluating and updating risk management plans, and where risk is deemed to be reduce, plans should be developed to bring the patient out of LTS, if this is indicated based on the risk formulation. Review processes should also include Assessment and Treatment Units (ATUs) seeking second opinions from other ATUs to challenge decision-making around LTS.

16. **Long-term segregation should be regularly reviewed by the MDT and nursing. This is one of the guidelines but I'd echo that cause I think that's good if it didn't exist, I'd be recommending it.**

17. **Regular reflective practice. Thinking about how LTS is working and to have other people from the MDT and other staff reflect on whether that approach is appropriate. So there are open discussions.**

18. **Reflective practice groups are good practice, where staff can speak freely.**

19. **Regular reflective practice discussion specific to LTS and restrictive practice, prioritising nursing colleagues and focusing on barriers to change. Making them moral agents and helping them reflect, so that they don’t become anaesthetised to the controversy, you know, long term segregation.**

Round 2 alternative combined guideline (original guidelines 17, 18, and 19).

Alternative guideline based on merging guidelines 17, 18, and 19:

Regular reflective practice specific to LTS that includes all MDT members involved in LTS, including healthcare assistants (HCAs). Discussions should cover issues specific to LTS, including restrictive practice, barriers to change, and whether LTS remains appropriate for the person being cared for in LTS. Reflective practice should help staff to maintain their moral agency and enable them to speak freely and openly.

20. **Exposure to other units and other practices. Learning from other units. Because a potential issue is isolation and development of insular culture. Fundamentally openness so staff can talk to other staff in other units.**

21. **Better resourced and better hospital environments made available to people with learning disabilities and autism. So that we’re not forced to make decisions to move people into long-term segregation. So these are actually better therapeutic environments for people to spend time in. It’s not bedrooms, communal areas, or seclusion and long-term segregation. You know… that there are other options available. For someone to be able to access other space with staff only, and where there's space for maybe staff to be with people. Not necessarily close to them. Umm, so it's less intrusive for the person who's wanting to isolate themselves. More spacious and varied therapeutic environments. And varied, in between communal living and long-term segregation.**

22. **A better equipped and designed low stimulus environment. It needs to have the opportunity of being locked down and changed so that people can go in and deliver a certain quality of care. By having separate rooms within LTS, you can have a day room so that you can go in and make sure the bedroom is clean ready for them to sleep; then you can have a lounge area that can be cleaned if that's where the dining table is and if that is where the activities are going to be based you can gear that up ready.**

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Extended paper

1. Extended Background

1.1 Terminology

The word “autism”[37] is used throughout this thesis as this is the term that research has suggested is most commonly endorsed by members of the autistic community (i.e. autistic people, their family, friends, and wider support networks that include

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[37] “Autism” is used in this thesis to refer to the entire autism spectrum and all it’s different diagnostic terms (i.e. Asperger’s disorder, Asperger’s syndrome, atypical autism, autism spectrum disorder, autistic disorder and pervasive developanellistental disorder-not otherwise specified (Chown, 2016).

professionals) when referring to or communicating about autism (Kenny et al., 2016; Chown, 2016). Furthermore, there has been much discussion and disagreement within the autistic community and among scholars regarding the use of either identity-first language (IFL, i.e. “autistic person/people”) or person-first language (PFL, i.e. “person/people with autism”; Botha et al., 2021; Bottema-Beutel et al., 2021; Sinclair, 2013). Following Botha et al. (2021), as well as members of the autistic community who also conduct research into the question of IFL versus PFL (e.g. Dwyer, 2022), the present thesis will use IFL (i.e. “autistic person/people”). Although there is no consensus within the literature about which terminology ought to be used, Botha et al. (2021) point out that there appears to be a consensus on the least preferred language, PFL, with research (e.g. Kenny et al., 2016) supporting this. As such IFL was chosen as this appeared to be most reflective of the wishes of the autistic community.

When referring to people without autism, the phrase “predominant neurotype” (PNT) will be used. This is related to the term “neurotypical”, however PNT avoids the assumption contained in "neurotypical” that there is one ideal “type” (Chown, 2016) of cognitive, sensory, and affective experience (Rosqvist et al., 2020). This choice directly links to the wider “neurodiversity” perspective, which has developed as both a self-advocacy movement and theoretical framework in psychology that challenges the view that autism is fundamentally a ‘disorder’ that necessarily requires intervention and treatment (Botha et al., 2021; Rosqvist et al., 2020; Sinclair, 2013). It is however acknowledged that not everyone who may be said to be part of the autistic community supports the neurodiversity perspective. Some community members, parent and advocacy groups believe that the neurodiversity perspective can minimise the profound difficulties that they themselves and/or autistic family members can face (Kenny et al., 2016; Bagatell, 2010; Humphrey & Lawis, 2008).

1.2 Scandals in the care of autistic people and people with intellectual disabilities

In 2011, the BBC exposed a scandal at Winterbourne View, in which autistic people and people with intellectual disabilities were subject to verbal and physical abuse whilst residing as inpatients in an independent sector hospital in Bristol (Taylor, 2021). In response to the Winterbourne View scandal, a range of policies were developed (e.g. the “Building the Right Support” and “Transforming Care” programme) aimed at enhancing community support, reducing inappropriate inpatient admissions, and reducing inpatient beds for autistic people and people with intellectual disabilities by 50% (Ince et al., 2022). However, numerous campaigning organisations (e.g. National Autistic Society, 2017; Mencap, 2019) identified continuing concerns around the care of autistic people and people with intellectual disabilities in inpatient care, such as abuse, and inappropriate use of restrictive interventions such as Long-Term Segregation (LTS) and seclusion (Ince et al., 2022). In 2019, BBC’s Panorama exposed another scandal at Whorlton Hall, again revealing systemic abuse of autistic people and people with intellectual disabilities within an Assessment and Treatment Unit (ATU). Such abuse included threats of violence, inappropriate use of restraint, and staff openly describing how they had physically hurt patients, such as banging a patient’s head against the floor (Richards, 2020).

The repeated scandals, and the systemic failures of government and institutions to address the abuses that autistic people and people with intellectual disabilities have faced, has led to multiple social action groups. For example, in 2016 the 7 Days of Action (https://theatuscandal.wordpress.com/) campaign was started to raise awareness of the people being held in ATUs and to advocate for their return to their communities. More recently, the Bringing Us Together movement started the Stronger Together project, with the aim of ending inpatient care for autistic people and people with intellectual disabilities through supporting families to feed into boards and consultation in the NHS, and lobby government. These movements call for fundamental change to the inpatient model of care (Richards, 2020). Attempts to reform the current system, for example through enhancing community care and reducing beds, seems to have failed. As such a fundamental shift in the way autistic people and people with intellectual disabilities are offered support and treatment is needed. However, fundamental change is not going to happen any time soon. As such, it is essential to ensure that informed, practical guidance is in place to reduce systemic harm to autistic people and people with intellectual disabilities as much as possible.

1.3 Restrictive Practices and Restrictive Interventions

Until recently, the terms ‘restrictive practices’ and ‘restrictive interventions’ have been used interchangeably within the literature (Lawrence et al., 2021; Hui et al., 2016). However, it has been recognised by researchers that it is important to distinguish two different definitions of these terms (Hui et al., 2016; Hext et al., 2018). As such, ‘restrictive interventions’ refers to specific measures taken to control service users that go beyond the routine norms of a hospital setting. These can include physical, mechanical, and/or chemical restraint (e.g. rapid tranquilisation), as well as seclusion and LTS (Hui et al., 2017). In contrast, ‘restrictive practices’ refers to the wider context of confinement, including the ward environment, ward routines, dynamics, and general atmosphere (Hui et al., 2017), including restrictive interventions (Lawrence et al., 2021). Furthermore, hospital admission in and of itself can be understood as an example of restrictive practice, as it significantly restricts a person’s autonomy and freedom (Clark et al., 2017). The routines and rules of hospital and ward environments also contribute to restrictive practices, as well as environmental aspects such as having little or no privacy, rigid mealtimes, exposure to lights and noises, as well as having to share space with other service users and staff (Hext et al., 2018; Jones et al., 2021).

Restrictive practices and restrictive interventions are often enacted when people are considered to be displaying, or are considered at risk of displaying, ‘challenging behaviour’ (Clark et al., 2018). Challenging behaviour is commonly defined as ‘Culturally abnormal behaviour(s) of such an intensity, frequency, or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities’ (Emerson & Einfeld, 2011, p.4). It has been pointed out that the inherently restrictive nature of psychiatric hospital and ward environments, such as the rigid rules and routines imposed on service users, may induce fear and uncertainty that then lead to ‘challenging behaviour’ that service users would not otherwise engage in (Whyte, 2016; Clark et al., 2018).

As such, it is important to understand that “challenging behaviour” or behaviours that challenge, arise from an interaction between the individual and their physical and social environment (Gallagher, 2004; NICE, 2015). If the environment that a person is in is experienced as hostile, negative, or even frightening, as is often reported by people residing on inpatient wards (Woods & Alsawy, 2016; Akther et al., 2019), it may be reasonably expected that people may display behaviours considered “challenging” as a means of protecting themselves from the perceived hostility of their surroundings. Furthermore, displays of behaviours that challenge may be expected to increase if the person has difficulties with social interaction and communication (often found in autism) and/or a learning disability (Murphy et al., 2005; Holden & Gitlesen, 2006). Studies have shown that a diagnosis of autism is a risk factor for the use of restrictive practices such as restraint and seclusion (Webber et al., 2014; Richardson et al., 2020). There may therefore be good reason to believe that restrictive interventions, including seclusion and LTS, are used disproportionately with inpatients who are autistic and/or have a learning disability (McGill et al., 2009; Jones et al., 2021).

1.4 Long-Term Segregation

One such restrictive intervention that may be used disproportionately with autistic people and/or people with a learning disability is long-term-segregation (LTS). The Mental Health Act (MHA) 1983 Code of Practice (Department of Health [DoH], 2015) defines LTS as "a situation where, in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation, a multi-disciplinary review and a representative from the responsible commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward or unit on a long-term basis". The MHA 1983 Code of Practice (DoH, 2015) provides basic guidance on how to legally implement LTS, along with generic guidance around for example making the environment “homely”, as well as ensuring that enhanced observations are implemented, and care plans aim to end LTS and re-integrate the person back into the main ward environment as soon as possible. As will be seen below, existing guidelines on the use of LTS specifically with autistic people may be inadequate to ensure good practice, in ensuring that the needs of autistic people are being met when in LTS. Whilst the MHA 1983 Code of Practice provides some basic guidance on the needs of children and young people in the context of LTS, there is no equivalent guidance using LTS with autistic people.

1.4.1 *Controversies in the use of LTS with Autistic People*

The use of restraint, seclusion and LTS with people with intellectual disabilities and autistic people in inpatient settings was subject to a review by the Care Quality Commission (CQC; 2020). The CQC were commissioned to carry out the review in light of increasing concerns related to human rights abuses of people with intellectual disabilities and autistic people, as well as concerns that many people are still subject to restrictive interventions (Joyce et al., 2021), despite there being a global consensus to reduce the use of restrictive interventions (Gaskin et al., 2013). Such abuses have been highlighted in reports such as the Winterbourne View report (2012), as well as other similar scandals of abuse and suboptimal care of people with intellectual disabilities and autistic people (Willis, 2020).

In terms of the CQCs findings of the use of LTS, they reviewed 66 autistic people across several inpatient psychiatric units in the UK and found that 53 of these people were in LTS. The CQC (2020) found that people were often subject to LTS not because they posed a risk to others (which is the reason within the MHA Code of Practice for using LTS) but because the ward environment was noisy and chaotic and causing them distress and as such was an inappropriate environment (Joyce et al., 2021). This finding is consistent with other research that shows that restrictive practices such as seclusion and LTS are more likely to be used with autistic people (e.g. McGill et al., 2009). This finding also highlights the dilemma that ward staff face when a person is admitted to a ward environment that is not suited to their needs. The report highlights how autistic patients often find the busy and noisy ward environment overwhelming and distressing, resulting in increases in behaviours that challenge (CQC, 2020). The only option staff are then faced with is to remove the person from the ward into seclusion, which could then turn into LTS as a means of managing risk to the patient and others.

Other notable concerns raised by the CQC related to people in LTS not being offered meaningful and/or therapeutic activities; varying understanding of what constituted LTS, meaning that people were not always protected by the MHA Code of Practice; lack of amenities, such as a table to eat at; people having few belongings or having overly restricted access to belongings; lack of good communication and/or staff leaving people alone for prolonged periods; frequent restrictions on families or friends visiting and restrictions on phone calls.

These findings validate concerns about the ongoing abuse and inadequate care of autistic people who are detained in inpatient settings and who are subject to LTS. The CQC (2020) concluded that:

> *Being placed in an inappropriate environment can be damaging and creates a pattern of distress, restraint and seclusion, which often cannot be broken. In many cases, we found that the impact of the environment on people, such as the noise, heating and lights of the wards, had not been considered. In many cases staff did not understand people's individual needs and the distress that being in the wrong environment could cause, particularly for people with sensory needs. This could lead to people expressing their distress in a way that others find challenging, leading to staff resorting to using restrictive practices (CQC, 2020, p. 13).*

The findings from the CQC (2020) also raise the issue of human rights abuses. For example, under the Equality Act 2010, all healthcare providers have a duty to make reasonable adjustments to the care they provide to disabled people. This can include for example, making adjustments to how to communicate with patients, or ensuring the environment is meeting their needs, such as making adaptations for people's sensory needs. The finding that this was repeatedly not happening makes it likely that people's human rights were breached.

1.4.2 *Inappropriate Environments and Unmet Needs*

The CQC (2020) report highlighted how when autistic people are placed in ward environments that are not suited their needs, this can trigger a process of increasing use of restrictive interventions (Williams et al., 2023) and abuses of human rights (CQC, 2020). Importantly, the report also highlighted how LTS was being utilised by staff teams not primarily because autistic patients were posing a risk to others, but because the main ward environment was too distressing and thus inappropriate. This use of LTS, as providing a more appropriate environment for an autistic person when the main ward environment is too distressing, is not currently specified within existing national guidance, such as the MHA 1983 Code of Practice (DoH, 2015). As such staff are placed in an uncertain clinical practice context that is not explicitly addressed by existing guidelines. This may lead staff teams to rely on clinical practices that are not suitable for meeting the needs of autistic people, as staff are reliant on current legal and practice frameworks that do not take into account the specific needs of autistic people. Conversely, there may be isolated incidences of good practice within specific units, where a person's needs have been taken into account in the context of LTS. For example, the CQC (2020) found some instances of more individualised use of LTS, such as a more personalised environment and a balance between staff presence and privacy. As such the CQCs findings suggest that the implementation and use of LTS varies widely between inpatient units, which may partly be the result of inadequate existing guidelines for the use of LTS with autistic people. As such this presents a gap between existing policy and practice that could have significantly harmful consequences for autistic people, and the people who work to support them.

There is therefore an urgent need to develop good practice guidelines when implementing LTS with autistic people. To elaborate on this crucial area further and highlight the importance of good practice guidelines that are clinically based, the needs of autistic people admitted to inpatient mental health settings will be reviewed. Major theories of autism will also be explored, and the lived autistic experience (Anderson-Chavarria, 2022) will be considered in the context of inpatient admission of LTS. Discrepancies between existing guidance and the needs of autistic people will also be highlighted.

1.5 Prevalence of autistic people admitted to inpatient mental health settings

Existing studies reveal that there is a significantly high number of autistic people admitted to inpatient psychiatric settings, in comparison to the general population (Tromans et al., 2018). More recent data from the National Health Service's (NHS) Assuring Transformation dataset showed that there were 2,030 autistic people and people with intellectual disabilities in inpatient mental health hospitals in England, of which 1,320 (64%) were autistic people (NHS, 2023). This number has increased from 38% in 2015. This is despite NHS England's 'Transforming Care' programme, which aimed to reduce the number of autistic people and people with intellectual disabilities in inpatient psychiatric settings and ensure that they can access the right support within their own communities (DoH, 2012). In 2015 the NHS published “Building the right support” (NHS, 2015), which laid out a national plan to close 50% of inpatient beds for autistic people with or without a learning disability and ensure that the right support would be developed within the community. However, this has not happened, and the continued lack of adequate community support is contributing to the increased numbers of autistic people and people with intellectual disabilities being admitted to inpatient settings (CQC, 2020; National Autistic Society, 2017). The rising numbers of autistic people and people with intellectual disabilities being admitted to inpatient settings amounts to a systemic failure to adequately support people to live freely in the community with the support they need. The increasing numbers of autistic people being admitted to inpatients settings also puts more people at risk of being subjected to inappropriate restrictive interventions, further necessitating the need to develop good practice guidelines for the use of restrictive interventions such as LTS with autistic people.

1.6 Understanding autism and the impact of inpatient admission and restrictive interventions on autistic people

The process of admission and detention on an inpatient ward is likely to be distressing for anyone (Chieze et al., 2019; Akther et al., 2019), and PNT people often report negative and frightening experiences when on inpatient wards (Woods & Alsawy, 2016). However, the experience of being placed on an inpatient ward, as well as being subject to restrictive interventions, is likely to be distressing for autistic people in specific ways that do not necessarily apply to PNT individuals. To understand this point in more detail, it will be necessary to consider what are generally accepted to be the key features of autism, as well as considering the mental health needs of autistic inpatients.

1.6.1 *Current understandings of autism*

Autism (also commonly referred to as “autism spectrum condition” within the scientific literature (Lai & Baron-Cohen, 2015)) is commonly understood as a neurodevelopmental “condition” (the term “condition” is quoted here rather than being merely stated as the use of the term is contended within debates about language preferences when speaking about autism, with some arguing that it minimises the way that societal structures create barriers for autistic people (Baker, 2011)). Autism emerges early in life (Lord et al., 2020; Varcin & Jest, 2017) and it is characterised by difficulties in social communication, social interaction, and social imagination (Wing, 1981; De Jaegher, 2013), as well as being characterized by repetitive, restricted, and stereotyped behaviours and interests (Lord et al., 2020). Many autistic people will also experience sensory sensitivities and difficulties with perceiving and integrating sensory information (Lai et al., 2020; Robertson & Baron-Cohen, 2017; Schaaf & Lane, 2015; Rogers & Ozonoff, 2005). These features of autism are generally understood to constitute "core" features of autism in the empirical and theoretical literature (Lord et al., 2020; Chown, 2016).

The identified difficulties in social communication, social interaction, and social imagination can be traced back to the idea that autism is characterised by a "triad of impairments" (Wing, 1981; Chown, 2016). Although there is disagreement among writers as to how best to define the triad (Chown, 2016), it is generally agreed that difficulties with social communication, interaction, and imagination (i.e., predicting other people's behaviour) are core features of autism. Furthermore, the triad links to one of the most influential theories related to understanding autism, theory of mind (ToM, Baron-Cohen, 1990). The ToM theory of autism states that autism can be understood as being the result of difficulties in autistic people's abilities to interpret the mental states of others and themselves (i.e. autistic people have an "impaired" or "absent" ToM) (Andreou & Skrimpa, 2020; Chown, 2016). A recent review of electroencephalography (EEG) studies (Andreou & Skrimpa, 2020) examining brain function in relation to ToM in autistic adults concluded that autistic adults do exhibit deficits in ToM, that these deficits were pronounced when in unfamiliar social situations, and that this would likely add to the burden of social communication for autistic people.

In addition to the importance of understanding the qualitative social-cognitive differences that some autistic inpatients may experience, there is also the need to consider the role of what has been called "restrictive and repetitive behaviours" (RRBs, Lord et al., 2020; American Psychiatric Association [APA], 2013). RRBs are part of the core criteria for assessing and diagnosing autism and encompass a wide-ranging set of behaviours that have been characterised as "invariant" in their manner and repetition, and which may appear “functionless” to an observer (APA, 2014; Lidstone et al., 2014; Leekam et al., 2011). Within the research literature RRBs have been categorised into “lower order” and “higher order” forms, with lower order being defined by stereotyped sensory-motor movements like body-rocking, whilst higher-order RRBs are associated with preference for repeated routines and specific interests or an “insistence on sameness” (APA, 2013; Bishop et al., 2013; Leekam et al., 2011). Furthermore, RBBs vary in their intensity and frequency among autistic people, with more frequent RRBs being predictive of severity of autism (Bodfish et al., 2000). Research into the underlying mechanisms and possible functions of RRBs has been limited (Berry et al., 2018), and at one point the research focus in this area was estimated as being as little as 10% of all autism research (Kasari & Lawton, 2010).

Multiple studies with both autistic adults and children have concluded that engagement in RRBs is associated with anxiety (Moore et al., 2021; Hwang et al., 2020; Kuzminskaite et al., 2020; Wigham et al., 2015; Lidstone et al., 2014; Jooston et al., 2010). Some of these studies (e.g. Kuzminskaite et al., 2020) have found that engagement in RRBs was a stronger predictor of anxiety than social communication challenges. In addition, autistic people have reported that they engage in RRBs for multiple reasons, including managing anxiety and uncertainty (Collis et al., 2022; Kuzminskaite et al., 2020; Knapp et al., 2019; Joyce et al., 2017). As such some studies suggest that RRBs can function as a means of regulating anxiety (Collis et al., 2022; Lidstone et al., 2014), which has been proposed to relate to the need to control one’s environment, maintain routines, and decrease uncertainty (Joyce et al., 2017). Finally, it is important to consider the specific sensory sensitivities that can be experienced by some autistic people.

Sensory differences in autism have been recognised since the earliest descriptions of autism emerged (e.g. Kanner, 1943). Sensory differences have been clinically observed in children as young as six months of age who were later diagnosed with autism (Baranek et al., 2013; Estes et al., 2015), and studies show that sensory reactivity differences persist into adulthood (Crane et al., 2009; MacLennan et al., 2021). Up to 94% of autistic adults are estimated to experience some form of sensory reactivity difference (Crane et al., 2009). Sensory differences range from hyper- to hypo-sensitivities. Hypersensitivities refer to sensory “overload”. In ward environments, this could be strong reactions to loud noises or the noise of groups of people on wards, the touch of other people such as staff, or ceiling lights that are unbearably bright (Williams, 1998). Hyper-sensitivity has been reported to be painful for some autistic people (Williams, 1998). Hyposensitivity refers to an underreaction in response to stimuli, such as a reduced response to pain (Pellicano, 2013). Hyposensitivity can lead to “sensory seeking” behaviours, where the person actively seeks out increased stimulation (Bogdashina, 2016; Pellicano, 2013), which can sometimes lead to self-injurious behaviours (Bogdashina, 2016). Sensory seeking behaviour may occur in an under-stimulating environment, such as LTS (CQC, 2020).

Finally, it is important to point out that the ToM theory of autism (i.e. one of the “big three” theories of autism, alongside the weak central coherence and the executive function theories of autism; Chown, 2016) has been contested in recent years as being too narrowly focused on higher-level cognitive functions (Chown, 2016; Markram & Markram, 2010; De Jaegher, 2013). Another key criticism of the ToM theory is that it fails to acknowledge that many non-autistic people have an equal amount of difficulty in interpreting the mental states of autistic people. As such, considering autism to be characterised by impairments in ToM is wrong if this same difficulty experienced by PNT people is not considered (the so-called double empathy problem, Chown, 2014). More recent theories, such as Intense World Theory (IWT) and enactive accounts of autism, emphasise the affective and fundamentally interpersonal aspects of autism (Markram & Markram, 2010; De Jaegher. 2013). Understanding the “situatedness” (De Jaegher, 2013) of the autistic person, is essential in highlighting how inpatient ward environments, and restrictive interventions such as LTS, may be particularly harmful and potentially traumatic for autistic people if the particular needs of autistic people are not taken into account.

1.6.2 *The impact of inpatient admission and restrictive interventions on autistic people*

Being placed in an unfamiliar context, such as an inpatient ward, where people are unfamiliar and can be unpredictable, has the potential to be particularly anxiety-provoking and distressing for some autistic people. Rates of anxiety are particularly pronounced in autistic people, especially social and generalised anxiety (Croen et al., 2015; Rogers et al., 2012; Simonoff et al., 2008). The increased rates of anxiety may be linked to difficulties with ToM skills related to social communication, interaction, and imagination (i.e. the triad, Lai & Baron-Cohen, 2015). PNT people often report negative and frightening experiences on inpatient wards (Woods & Alsawy, 2016; Akther et al., 2019). Negative and frightening experiences are likely to be amplified for some autistic people admitted to inpatient settings because of the nature of the ward environment and the challenges associated with difficulties in interpreting and responding to the social world, as well as differences in regulating sensory inputs. This could well result in increased anxiety responses in ward settings, leading to heighted distress, as autistic people may struggle to interpret the actions of other patients and staff on the ward, or react strongly to the physical environment itself, such as bright ceiling lights. Furthermore, intolerance of uncertainty is thought of as one of the key factors associated with heightened levels of anxiety experienced by autistic people (Robertson et al., 2018; Maisel et la., 2016; Boulter et al., 2014). Given the difficulties in autism with interpretating social information, this is likely to lead to an increased sense of uncertainty in the inpatient setting, where there is likely to be immediate uncertainties relating to how other people (patients and staff) are going to behave, as well as more distal uncertainties relating to length of stay and discharge (Maloret, 2020; Chaplin, 2004). As such this could result in increased distress, which may then lead to the increased use of restrictive practices, such as Long-Term Segregation (LTS), such as that found in the CQC (2020) report.

Furthermore, an autistic person’s specific sensory differences may interact with the ward’s physical and social environment to increase distress. Studies have found that the sensory profile of inpatient settings can be a source of anxiety for autistic people (Maloret & Scott, 2017). Bright lighting, the strong smell of cleaning products, noise from other people, the sound from air conditioning units, and the texture of hospital foods have been found to be sources of anxiety for autistic people in inpatient settings (Maloret & Scott, 2017). Furthermore, the lack of control over the sensory profile of the ward was a key feature in the distress caused by being in an inpatient setting for autistic people. For example, participants in the Maloret and Scott (2017) study reported being continually disturbed by the closing and opening of doors, or when touch was used by staff to limit movements, which resulted in heightened stress and behaviour such as withdrawal from staff. For some autistic people, the sensory profiles of ward environments are likely to increase anxiety (Hwang et al., 2020) due to the lack of control over sensory inputs.

When considering the role of RRBs in the inpatient context, Lidstone et al. (2014) suggest that RRBs can become increasingly intense when anxiety increases. Within an inpatient setting, that can be highly unpredictable and noisy (Maloret & Scott, 2017; Murphy & Mullins, 2017; Donner et al., 2010), it can be expected that engagement in RRBs is likely to markedly increase for some autistic people as they attempt to manage the stress of the situation. Furthermore, some autistic people experience an “exaggerated” response to internal bodily sensation, and some studies have documented that some autistic people will attend to internal sensations for prolonged periods of time (Schauder et al., 2015). This may result in an intense awareness of anxiety that may then increase RRBs (Edelson, 2022). In a ward setting, this could be interpreted by staff as noncompliance with ward routines, which could then lead to increased use of coercive and restrictive interventions with autistic people, such as LTS (Jones et al., 2021). A consequence of this could be that the autistic person attempts to suppress their RRBs, because of negative reactions from staff. Suppression of RRBs has been reported by autistic people as stressful, which over time could have a negative impact on mental health and functioning (Collis et al., 2022).

Finally, it is crucial to consider the potentially traumatic impact of restrictive interventions can have on autistic people. Multiple studies have shown that restrictive interventions are an emotionally distressing and potentially traumatic experience for patients and staff (Bonner et al., 2002; Wynn, 2004; Lawrence et al., 2021). Research suggests that autistic people are more likely to report symptoms of Post-Traumatic Stress Disorder (PTSD) compared to the general population, with studies suggesting that rates of PTSD in the autistic adult population range between 32-45%, compared to 4-4.5% in the general population (Haruvi-Lamdan et al., 2020; Rumball et al., 2020; Rumball et al., 2021). Autistic people are also at increased risk of experiencing traumatic events and of having adverse childhood experiences (ACEs; Dodds, 2020; Fuld, 2018). As such, the use of restrictive interventions such as restraint and LTS is likely to pose a serious risk of causing traumatic harm and/or re-traumatising autistic inpatients.

It is also important to note that trauma may be experienced differently by autistic people. Intense World Theory (Markram & Markram, 2010) posits that autism leads to an increased intensity of response to environmental stimuli, with autistic people responding to events more acutely than PNT people. This means that autistic people may be more vulnerable to experience stressful events as overwhelmingly stressful and traumatic. This may also mean that events that fall outside of commonly accepted definitions of trauma may be experienced as traumatic by autistic people (Dodds, 2020), due to an overall experience of the world as painfully intense (Markram & Markram, 2010). As such, events such as being admitted to an inpatient ward, having repetitive or preferred behaviours discouraged or prevented by staff or the physical environment, or having one's routine disrupted by being moved into or out of LTS, may constitute traumatic experiences for autistic people (Fuld, 2018; Kerns et al., 2015).

1.7 The limitations of existing guidelines for implementing LTS/The need for a coherent framework for implementing LTS with autistic people

The above considerations suggest that for autistic people, the nature of an inpatient setting places them at increased risk of being subject to restrictive interventions, in particular LTS. This increased risk is related to the autistic person being placed in an inappropriate environment that is not suited to their needs. This then can lead to increased distress and increased displays of behaviours that challenge staff and/or put the person or others at risk of harm. This leaves staff in a difficult position, as the only option they may have is to remove the autistic person from the main ward environment into a separate area. It is conceivable that placing an autistic person into LTS may result in a reduction in distress, as the ward environment may for example produce a sensory overload, whereas the LTS environment by comparison may be experienced by the autistic person as calming or at least significantly less distressing. As such staff may feel that the LTS environment is more suitable in comparison to the main ward environment for some autistic patients. Conversely, the LTS environment may be too under-stimulating for some autistic people, particularly if the persons specific sensory needs are not taken into account. As such, autistic people in ATUs may be moved from one inappropriate environment to another, with only brief periods in which the caring environment is meeting their needs. This process may be exacerbated in the absence of a coherent framework for implementing LTS with autistic people.

Therefore, being placed in LTS may be meeting some of the needs of the autistic person, for example their need to be in low stimulus environment or to have a space that is not populated by anyone else. However, existing guidelines on the use of LTS (i.e. the MHA Code of Practice) stipulate that as soon as LTS begins, a plan should be developed to end LTS and integrate the person back into the main ward environment. The guidelines state that the decision to end LTS should be made on the basis of assessing that ongoing risks have reduced sufficiently to allow the person to return to the main ward. This places staff in a clinical dilemma, as the persons risks may have reduced, or they may even have not presented with any overt risks as such but have been placed in LTS because of the distress caused by the main ward environment (CQC, 2020). But returning the person to the main ward environment may not be an appropriate clinical choice, as this may then reinstate the distress and/or behaviours that challenge that lead to the use of LTS in the first place. Arguably the choice to return someone to the ward environment when that environment is demonstrably distressing for them represents an unethical choice. However, the ongoing use of LTS may itself lead to the persons needs not being met, given the restrictive nature of LTS.

As such, existing guidelines on the use of LTS with autistic people fails to adequately consider the specific needs of autistic people in an inpatient environment. What is required therefore are a set of clinically based, good practice guidelines that can help staff move towards good practice in the use of LTS with autistic people, ensuring that the persons needs are met when in LTS, as well as protecting them from abuses of their human rights. There are currently no existing evidence-based guidelines that could support staff to effectively implement LTS with autistic people.

1.8 The role of the Clinical Psychologist

In addition to being trained in delivering individual psychological interventions and treatments, Clinical Psychologists are also expected to work at systemic levels, applying the science of psychology to address human problems. This aspect of the role of the Clinical Psychologist is described by the British Psychological Society (BPS, 2010) as working with groups, individuals, and organisations. A key element in working at a systemic level is related to utilising “research competence and the critical evaluation of research activity” (BPS, 2010, P.3), skills which are recognised as being increasingly in demand by healthcare commissioners and service organisation (BPS, 2010). Furthermore, the BPS (2010) emphasise that Clinical Psychologists play an important role in developing interventions and activities that are informed by an integration of theory, research, and practice. As such research is fundamentally woven into good clinical practice, and Clinical Psychologists are well placed to develop aspects of clinical practice at multiple levels, informed by psychological theory and systemic research approaches (BPS, 2010). What this means is that Clinical Psychologists can address problems that arise at different levels, such as at a service level when implementing LTS. Clinical Psychologists can then develop new clinical practices or applications that can be applied by others such as inpatient mental health staff. Therefore, Clinical Psychologists are in a good position to develop good practice guidelines to help staff move towards good practice in the use if LTS with autistic people.

1.9 Practice-based evidence and evidence-based practice

Evidence-based practice (EBP, otherwise known as evidence-based medicine) has become increasingly incorporated into many healthcare disciplines over the last 25 years, owing to an increased recognition over issues such as the gap between evidence and practice, and the disparity between current knowledge and clinical performance/judgement (Straus et al., 2018). The EBP paradigm rests on the foundation of efficacy research, with the randomised controlled trial (RCT) being regarded as the epitome of efficacy research (Barkham & Mellor-Clark, 2003). The proponents of the EBP paradigm argue that it can help shift healthcare practice away from intuition and unsystematic clinical practice towards a more scientific approach to medicine (Knaapen, 2013). Through providing clinicians with “evidence” delivered by rigorous research trials, EBP aims to manage the way uncertain or ambiguous clinical situations are addressed (Armstrong, 2007). Although originating in medicine, as stated above, the EBP paradigm has moved out into other healthcare areas, including mental health.

However, it can be argued that while the EPB paradigm may be effective in the context of medicine, where understanding of the underlying mechanisms of pathologies is well known, and the potential harm from poorly tested interventions is high (Green, 2008), the EBP paradigm may be less suited to the complexities of mental healthcare in inpatient settings. In many mental health settings, such as inpatient wards, specific psychological, cultural, and contextual constraints may have considerable influence over the relationship between interventions/clinical practices, and outcomes (Green, 2008). In these settings, external validity becomes just as important as internal validity and experimental control (Green, 2008; Green, 2006). The EBP paradigm typically prioritises internal validity (i.e. the extent to which causality can be inferred between variables) and experimental control, whilst neglecting external validity (i.e. the extent to which a study's findings apply to settings outside the research context, Knappen, 2013; Green, 2006). As such the EBP paradigm may not be a suitable approach when attempting to address clinical issues in complex settings such as inpatient assessment and treatment units for autistic people.

Furthermore, empirical studies examining the use of EBP approaches to handle uncertainty show that the clinician's clinical knowledge, skills and experience are not simply removed, with EBP standards filling the gap (Berg & Timmermans, 2000). Rather, clinicians rely on a combination of evidence and clinical experience and judgement (Timmermans, 2004), with clinicians relying on local and incomplete knowledge to inform practice (Knaapen, 2013). These findings are consistent with the argument put forward by Thornton (2006), which suggests that even EPB, translated into clinical guidelines, fundamentally rests on "good judgement", understood as consisting of tacit knowledge and skills gained from experience. Not only is the importance of good clinical judgement recognised by existing guidelines, such as the NICE guidelines (2020), but it is also consistent with the concept of practice-based evidence (PBE).

PBE can be understood as a bottom-up approach which contrasts with the top-down approach offered by the EBP paradigm (Barkham et al., 2010). PBE can be defined as a means of building an evidence base that is driven by local questions and clinical contexts, but which can also feed into and inform national issues (Barkham et al., 2010). A more explicit definition has been offered by Barkham and Margison (2007) who define PBE as "the conscientious, explicit, and judicious use of current evidence drawn from practice settings in making decisions about the care of individual patients. Practice-based evidence means integrating both individual clinical expertise and service-level parameters with the best available evidence drawn from rigorous research activity carried out in routine clinical settings" (Barkham & Margison, 2007, p.446). Accordingly, the PBE approach can be seen as a more contextually relevant approach to building an evidence base that is situated in local clinical settings, and therefore as having high external validity (Barkham & Mellor-Clark, 2003). The PBE approach has been increasingly incorporated into the field of psychotherapy (Barkham et al., 2010), where for example it has been shown to improve practice in service contexts by increasing practitioner reflection and generating evidence that is specific to the service context (e.g. Lucock et al., 2003; Paley et al., 2008).

Although being used increasingly in psychotherapy contexts, the PBE evidence approach is used less in other areas such as inpatient mental health settings and in indirect work in Clinical Psychology. However, there remains an important question relating to finding better ways of producing new knowledge that is relevant to practice that can be utilised by staff (Gabbay & Le May, 2011). This question is highly relevant in the context of using LTS with autistic people, as this particular clinical context often presents complex clinical issues for which there currently exists no adequate evidence-based guidance. To produce new knowledge, there may be a need to move towards more collaborative research in a PBE approach that breaks with traditional notions of detached research (Fox, 2003). The present study was developed in line with a PBE approach that recognises the need for finding new ways to produce clinically relevant knowledge that can be utilised by mental health staff.

1.10 Clinical practice guidelines and clinical mindlines

An integral component of the EBP paradigm is the development and utilisation of clinical practice guidelines (Lander & Balka, 2019; Weisz et al., 2007), defined as ‘‘systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances.’’ (Graham & Harrison, 2005, p.68). Despite the large number of resources utilised to develop and produce guidelines (Barth et al., 2016; Eby, 2016; Grol & Grimshaw, 2003), studies have repeatedly found that in practice, clinicians do not consult clinical practice guidelines, but rather they rely on "mindlines" (Wieringa & Greenhalgh, 2015;

Gabbay & Le May, 2011, 2004). Over the course of two years, Gabbay and Le May (2004) observed and interviewed staff within GP practices (doctors, nurses, and associated medical staff) to study how they arrive at their individual and collective healthcare decisions. What they found was that clinicians would rarely consult explicit evidence from research, instead relying on “mindlines”- “collectively reinforced, internalised, tacit guidelines” (Gabbay & Le May, 2004, p.1). Mindlines were informed mainly through interactions with colleagues, opinion leaders, brief reading, and patients, and consisted of largely tacit knowledge built from early training and their own and colleagues experiences. Furthermore, mindlines were refined mainly through interactions with colleagues, rather than consultation with explicit guidelines (Gabbay & Le May, 2004). In contrast to clinical practice guidelines, mindlines can be used to make rapid decisions when required within a complex clinical context, because they are more malleable and flexible than explicit guidelines (Gabbey & Le May, 2011).

The aim of the present research is to harness the clinical reality of mindlines to address the knowledge gap between existing guidelines/policy, and practice in the context of using LTS with autistic people. Therefore, the study will aim to develop a set of clinically based, contextually sensitive good practice guidelines that staff can flexibly utilise to move towards good practice in the use of LTS with autistic people. The aim is not to produce clinical practice guidelines, which often are not consulted by clinicians (Gabbay & Le May, 2004). Rather, the aim is to draw on the experiential knowledge of healthcare professionals in similar but differing contexts so that local clinical mindlines can be shared beyond the limits of local practice, and in doing so foster the social distribution of clinical knowledge (English, 2020; Gabbay & Le May, 2004, 2011). The Delphi Method (Barrett & Heale, 2020) was used as a means to extract this clinical knowledge.

Finally, the knowledge that was obtained from the Delphi panel and the guidelines that were finalised were not intended to be understood as “facts”, but rather as the beginning of a process of developing “socially constituted knowledge” (Gabbay & Le May, 2004) in relation to the use of LTS with autistic people. This is consistent with the view that clinical mindlines are not merely “disseminated” or “translated” into clinical practice, but rather that they are enacted and shared within specific contexts, with knowledge being re-created in different contexts (Wieringa & Greenhalgh, 2015;

Gabbay & Le May, 2011). As such the Delphi process was intended to initiate a process of developing a clinically based knowledge of the good practice of LTS with autistic people, that could be shared and continually refined through repeated sharing and application within different contexts. In this way inpatient mental health staff could begin to make explicit their implicit clinical knowledge of good practice and then distribute it to others.

2. Extended Method

2.1 Methods of consensus building

Consensus building is a process of generating ideas to address complex issues where there currently exists no clear agreement about how to respond (Black et al., 1999; Keeney et al., 2011). The aim of consensus building methods is to synthesise the views and perspectives of group members in a way that overcomes the disadvantages typically found in group decision making, such as the disproportionate influence of single individuals or the bias of coalitions with their own interests (Black et al., 1999; Jones & Hunter, 1995). Consensus building methods seek to reach a convergence of opinion around a topic where there may be uncertainty or where practice varies widely (Black et al., 1999; McMillan et al., 2016). In the field of healthcare, three formal consensus methods have been developed. These are the nominal group technique (NGT), the consensus development conference (CDC) and the Delphi method (Black et al., 1999; World Health Organisation [WHO], 2014; McMillan et al., 2016).

The NGT uses a highly structured group meeting of relevant experts (typically 7 individuals) to collect information about a specific issue, by enabling group members to voice their own ideas and opinions about the matter at hand and to have each other's ideas considered by other group members (McMillan et al., 2014, 2016; Jones & Hunter, 1995). The NGT consists of four stages: silent generation of ideas and viewpoints in response to the question or issue, a round robin where ideas are stated by each group member and recorded by the facilitator, clarification, where ideas are clarified, similar ideas grouped together, and some excluded or altered, and voting, where group members rank the top preferences among the ideas generated (Gustafson et al., 1986). The goal is to achieve group consensus through group discussions and interactions, facilitated by an expert on the topic or a credible non-expert (Hunter & Jones, 1995).

NGT was considered as inappropriate for the present study, firstly because the nature of the expert panel meant that some members (such as Psychiatrists, Ward Managers) may possess more perceived power and/or knowledge than other members such as Healthcare Assistants. Studies have found that hierarchical team structures, such as that present in the National Health Service (NHS) can have inhibitive effects on team members, such as nurses, voicing suggestions (Krenz et al., 2020). Even though there are elements of anonymity in NGT, for example in terms of voting, there may still be powerful social dynamics that may inhibit some members (Vander Laenen, 2015) during a face-to-face meeting. Furthermore, NGT is designed as a single-use technique within a live meeting, and as such provides group members with only a limited amount of time to consider their own viewpoints and that of others (Hamilton, 2021; Vander Laenen, 2015). This may be inappropriate for addressing more complex issues such as developing clinically based guidelines, which may require a more detailed and systematic process.

CDC involves the convening of a meeting of usually ten people to try to reach consensus on a given issue. Group members meet over the course of several days and listen to evidence presented by various interest groups on the issue at hand. Presenters are not group members, but experts on the given issue and do not have a role in decision-making (Black et al., 1999; WHO, 2014). The expert panel then meet after the presentation to consider the question/issue in light of the evidence presented and are asked to try to reach a consensus (Campbell et al., 2002; Halcomb et al., 2008; WHO, 2014). There is no formalised structure to the interaction of the group and no private decision-making stages (Black et al., 1999). Therefore, the CDC approach is much less structured and formal compared to both NGT and the Delphi method. As such the CDC was deemed unsuitable for the present study, as the lack of structure meant there was no way to manage social dynamics that may influence the process of reaching consensus. Additionally, the CDC approach relies on an implicit group process to come to a consensus on a given topic. This is not adequate when the aim is to produce a set of specific guidelines (Murphy et al., 1998).

A more explicit methodology that utilises a systemic process of collecting ideas and anonymously sharing them was required. As such the Delphi method was chosen, as it offered a systemic means of building consensus, ensuring anonymity, and not requiring group members to meet in person. Given the nature of the topic it was likely that there would be a need to reach out to participants who were spread across the country in different ATUs. As such the Delphi method enabled the expert knowledge and experience of a group of mental health professionals from across the country to be collected together from a variety of service contexts using LTS whilst retaining a systematic and rigorous process of consensus building.

2.2 The Delphi method

In the classic Delphi method (Barret & Heale, 2020; Keeney et al., 2011), a group of participants (in the Delphi method referred to as “panellists”) considered to be experts on a given topic are asked to respond to a series of carefully designed surveys (known as “rounds”). Panellists are asked to indicate their view on each item within the survey on a Likert scale, as well as provide qualitative feedback. Additional qualitative feedback is intended to contextualise panellist responses and facilitate anonymous communication between panellists (Brady, 2015). Responses from each panellist are collated by the facilitator (the researcher) who then sends a summary of the previous round back to participants which presents the group consensus for each item. If consensus has not been achieved after a round, panellists can amend their initial responses in light of how other panellists responded and in light of any additional feedback panellists have provided. As such the Delphi method can be understood as a multi-stage process where each stage is built based on the previous stage (Sumsion, 1998).

The present study utilised a ‘classic’ Delphi method in which the aim was to establish consensus among the panel, in this case to establish consensus on a set of good practice guidelines that can be used to inform practice in the use of LTS with autistic people. As a minimum requirement Delphi’s have at least two rounds as a means for providing feedback to panellists and facilitating the option to revise earlier responses (Thangaratinam & Redman, 2005; Mckenna, 1994). Beyond that however, the number of rounds considered appropriate is disputed within the literature. Although one of the principles of Delphi’s is to have as many rounds as are needed to reach consensus (Mckenna, 1994), most Delphi studies use between three and five rounds maximum (Thangarantinam & Redman, 2005). The present study utilised three rounds with a final fourth round to elicit feedback from panellists on the finalised guidelines. This choice was made based on previous Delphi studies, as the existing literature indicates that consensus can often be achieved within three to five rounds before attrition becomes a significant problem (Brooks, 1979; Custer et al., 1999; Walker & Selfe, 1996).

2.3 Delphi method and group effects

Delphi researchers have postulated that group decisions are more reliable than decisions made by individuals and that the opinions of experts, when elicited with respect to a predefined problem, are more objective than individual statements (Franklin & Hart, 2007; Lang, 1995; Murry & Hammonds, 1995). This is consistent with the view of Hill (1982) that “n+1” heads are better than one, as the total amount of useful information available to all group members is likely to be greater than that of any one person within a group (Rowe et al., 1991). However, studies have shown that group judgement is often inferior to the groups best or strongest member (Hastie, 1986; Hill, 1982). Various explanations have been offered to account for this effect, referred to as a “process loss” (Steiner, 1972). Social pressures may be exerted on some members over others, or there may be a lack of contribution from less confident but nonetheless competent group members, which bias the group outcome (Steiner, 1972). Furthermore, it may be that group motivation shifts from achieving the best possible judgement to simply reaching agreement as soon as possible in a way that does not offend anyone (Janis, 1972; Hoffman, 1965).

A strength of the Delphi method is that it can directly counter the negative aspects of interacting groups, such as social pressure, whilst retaining the positive aspects, such as knowledge from a wide range of individuals (Rowe et al., 1991). The negative impact of factors such as status or social desirability are reduced through the Delphi’s use of anonymity (Sumsion, 1998; Nelms & Porter, 1985). As such the Delphi method can offset “process loss” and potentially lead to “process gain” if the method is applied in a robust manner, by ensuring anonymity, using iteration (of rounds) to foster deliberation, and using feedback to stimulate reflection (Rowe et al., 1991). The Delphi method may also be particularly useful when asking Multidisciplinary Team (MDT) members in NHS settings to make group decisions and judgements, as studies have shown that the existing medical hierarchy within such settings produces power imbalances that disproportionately favour some views over others (Rogers et al., 2023).

2.4 Design of Delphi rounds

It is generally accepted that between three to five rounds are sufficient in a Delphi study to reach consensus on a given issue (Custer et al., 1999), with the first round typically being used in an open-ended way to elicit information about a specific area or problem from the expert panel. However more recent approaches to the Delphi method have chosen instead to review existing literature on a given topic or issue, and then develop a survey based on a literature review, rather than consulting the panel in the first instance (Nurek et al., 2021; Chen et al., 2013; Balogh et al., 2011; Fry & Burr, 2001). However, the approach of consulting the existing literature is not possible in areas where there is little established research, and a strength of the Delphi method is that it can provide a way of developing new knowledge and understanding in areas where that is little or no literature (Martino, 2018). In the area of the use LTS with autistic people, there is very little research, and no research that looks specifically into how best to utilise LTS with autistic people. The lack of existing research was a key reason the Delphi method was employed in this study. Furthermore, pre-defining the content of the round one survey on the basis of existing literature would limit the opportunity for developing new, practice-based knowledge that can be utilised by staff (Gabbay & Le May, 2011). A key aim of the present study was to harness a diverse range of experiences and expertise to address the gap between existing policy and guidance in the use of LTS and the complex clinical situations of caring for autistic people when using LTS. As existing literature cannot address this problem, the first part of the present Delphi study consisted of semi-structured interviews with panellists to elicit information that would be used to develop the Round one survey. Panellists were asked to provide three good practice recommendations each, that would be included in the anonymised survey.

Finally, another important consideration when designing the survey rounds was related to how the researcher translated the data from the interviews to the round one survey, and then the round one survey data into the round two survey and so on, without compromising the validity of the process (English et al., 2020). There is a risk that researcher interpretations of data can compromise the Delphi process by introducing researcher bias into the process, for example by qualitatively analysing data and then presenting themes in subsequent rounds to summarise the data (Okoli & Pawloski, 2004; Schmidt, 1997). To avoid the potential of researcher bias compromising the Delphi process, data (i.e. good practice recommendations and subsequent panellist comments during survey rounds) was moved between rounds without any interpretative analysis being completed.

2.5 Interview schedule design

The process of designing the interview schedule for the interview phase of the Delphi study was based on previous Delphi studies that had explored areas with little established research and which focused on the development of good practice guidelines (e.g. English et al., 2020; Taylor, 2020). As one of the aims of the study was to bring together a wide range of experiences and opinions on best practice in the use of LTS with autistic people to develop a set of good practice guidelines in the use of LTS with autistic people, the interview schedules for both MDT members and parents/carers (See Appendix J and Appendix K) were developed to have an open-ended format. Through discussions with the research team, the questions were developed to be open, exploratory, whilst being centred around experiences of the use of LTS with autistic people. Interview questions elicited information related to examples of times when the use of LTS went well and benefitted the patient, as well as times when it did not go well. Follow up questions asked about what factors related specifically to LTS, the wider ward environment, and factors related to the patients care, contributed to good and not so good outcomes. Finally, based on an exploration of the interviewee’s experiences, interviewees were asked to provide three recommendations for good practice in the use of LTS that would be fed back in the anonymised survey round. Due to the lack of existing knowledge on this topic, a decision was made to make all guidelines explicit to panellists in the round one survey without any interpretation and adhering to panellists’ own language, apart from making changes to grammatical errors where necessary. This was done through re-listening to audio recorded interviews and checking the wording of each recommendation. This was done to avoid biasing the data.

2.6 The expert panel

Choosing the expert panel is considered to be one of if not the most important part of the Delphi process (Keeney et al., 2011; Donohoe & Needham, 2009). However, what constitutes an “expert” is a debated point within the Delphi literature and the term is heavily contested (Turoff & Linstone, 2002; Hasson et al., 2000; Sumsion, 1998). Within the Delphi literature, “expert” has been defined as anyone who is knowledgeable about a specific topic (Green et al., 1999), whereas others have defined expert as anyone who is “informed” about the area concerned or anyone regarded as a “specialist” in their field (Green et al., 1999; Davidson et al., 1997; McKenna, 1994). As such there is no agreed upon definition of “expert” across Delphi literature (Sumsion, 1998), and as such there is a risk of bias entering into the selection process (Thangaratinam & Redman, 2005). A key responsibility for the researcher is to explicitly define the inclusion and exclusion criteria when selecting the panel (Sumsion, 1998). Keeney et al. (2011) suggest that the expert panel should be made up of people who have both good theoretical knowledge and clinical experience of the specific issue. The suggestion of Keeney et al. (2011) is consistent with the practice-based evidence approach of the present study, and as such informed the decision to form a panel who had both knowledge of the area and clinical experience.

As such the panel was formed by discussion within the research team and focused on considering who would be best placed to offer both knowledge of the use of LTS with autistic people as well as being able to draw upon their own experiences of the use of LTS with autistic people. The outcome of these discussions was that MDT members (e.g. nurses, healthcare assistants, occupational therapists etc) with clinical experiences of the use of LTS with autistic people, and parents/carers of autistic people who have been in LTS were the most appropriate in terms of knowledge and experience. This definition of "expert" with the present study was in line with guidance developed by Baker et al., (2006), which included definitions of knowledge and experience. As part of the research teams discussions, we spoke about the inclusion of service users (i.e. autistic people who have experience of being in LTS) on the panel. After careful consideration we decided not to include service users in the study. This was related to the legal aspects of LTS and the technical aspects of the Delphi process.

Due to the complexity of the use of LTS with autistic people, we felt it necessary to impose a minimum threshold of at least one year's clinical experience in an MDT role that included working with autistic people in LTS. Although this threshold could be criticised as being arbitrary and not necessarily indicative of "expertise" (Hamilton, 2021), we felt it was important to ensure that MDT panellists had a minimum level of clinical experience to be able to offer practice-based information and input into the Delphi process given the topic was niche. We also aimed to recruit a group that was as representative as possible of a typical NHS MDT, to ensure that as wide a range of relevant professional perspectives were represented within the study.

Finally, it was important to carefully consider the size of the panel. There is no agreed upon optimal size of a panel within the Delphi literature, and Delphi studies have been completed with panels ranging from between four to 3000 panellists (Jorm, 2015; Thangaratinam & Redman, 2005). However, the quality of the panel is not determined by the number of panellists, but rather by the relevance of the panellist's knowledge and experience in relation to the topic (Keeney et al., 2011; Powell, 2003). Furthermore, it has been suggested that for Delphi studies, increases in reliability in panels of more than 15 are small (Murphy et al., 1998). Another factor to consider when determining the size of the panel is the possibility of attrition, which can occur in Delphi's due to the time commitment required by panellists and time between rounds (Hanafin & Brooks, 2005). As such, given the need to protect against significant levels of attrition, which may invalidate the consensus process (Bardecki, 1984), alongside the niche topic area, it was decided that we would aim to recruit 15-22 panellists, with the majority being MDT members (as they would be most likely to directly implement the finalised guidelines), and at least two carers/parents.

Another means of minimising attrition in Delphi studies is through personalised and regular communication with panellists throughout the process. From the start and through the Delphi process, panellists were sent regular emails informing them of the next steps of the process, timelines for the study, and emails prompting panellists of upcoming survey deadlines (Donohoe & Needham, 2009). Furthermore, panellists were also given sufficient time to complete and return surveys in each round (15 working days in total), and in Round 2, the turnaround time was extended to account for Bank Holidays.

2.7 Removing and modifying items with the Delphi method

At present there are no guidelines relating to the process of modifying and/or removing items in a Delphi survey, with decisions about removing items tending to be arbitrary (English et al., 2020; Wells, 2021). Following English et al. (2020), in order to avoid arbitrarily introducing bias into the process by removing items between rounds that had not met consensus or removing items if they had achieved consensus that they were not “essential”, no items were removed between rounds (Hasson et al., 2000). This decision was made to promote transparency and reduce bias by not filtering the information provide to the panel. By providing the panel with all the information available within each round, they were enabled to re-evaluate their initial responses in relation to the decisions and comments of other panellists (Hsu & Sandford, 2007). This level of transparency arguably enabled consensus to emerge organically rather than consensus being forced through manipulation of available information (English et al., 2020).

To further counter the introduction of bias, any merged or combined guidelines were presented alongside their original guidelines and the panel were asked to re-rate the merged guidelines. These modifications to guidelines were considered significant and as such the panel were required to re-rate the guidelines. Modifications (merging or combining two or more guidelines) were made when multiple panellists (defined as two or more) identified a significant overlap or similarity between guidelines, or when panellists made similar suggestions. Minor modifications, such as slight changes to the wording of a guideline, were again made when panellists and/or research team members identified a need for this, but these guidelines did not require re-rating if they had achieved consensus. Minor changes were made clear to panellists through italicising the changes and explaining what the italics indicated in the email to panellists at the start of each round.

Where an alternative or combined guideline was presented, panellists were asked to indicate if they thought the original guideline (or guidelines in the case of a combined guideline) should be replaced by the new guideline. Consensus criteria for replacing guidelines was 80% panellist agreement.

Finally, there were several instances of minority views that suggested possible changes to guideline wording. The presence of such minority views may have reflected reduced pressure to conform to the majority view owing to the anonymity of the Delphi design. The researcher carefully attended to these comments, however there is little guidance in Delphi literature on how to manage minority viewpoints, and it has been suggested that minority views can be ignored by the researcher (Turoff & Linstone, 2002; Dalkey & Helmer, 1951). As stated above, panellists suggested changes were acted upon and incorporated into the guidelines when two or more panellist’s expressed similar suggestions (Wells, 2021).

2.8 Asking specific questions of the panel

There were two instances, in Round three and Round Four (See Appendices O and P for examples), where specific questions for further information were asked of the panel. The first instance concerned clarifying the meaning of a specific guideline that made reference to “everyone” being involved in how LTS is begun. Panellists were asked to comment on how they think “everyone” should be defined so that the guideline had greater clarity. Three panellists (panellists 7, 10, and 12) responded directly to the question. Panellists 10 and 12 suggested that “everyone” be defined as the MDT where available. Panellist 7 also suggested “everyone” refer to the MDT but suggested that not everyone will be able to be “decision makers”. The guideline that the question referred to (14) did not reach consensus to be included in the final guidelines.

The second instance occurred in Round Four, where panellists were asked to provide details of the guidance and/or policies they and their MDTs use when reviewing LTS. Two panellists (3 and 12) responded directly to this question. Panellist 3 spoke about their MDT designing plans to ensure that the patient, staff, and prospective care providers are aware of how to effectively involve the patient in their care. But it was not clear how these plans were used to review LTS. Panellist 12 said that they do not use specific criteria and described using a combination of clinical expertise and guidance around best practice, making reference to capable environments (e.g. McGill et al., 2020), as a means of evaluating LTS.

2.9 Defining consensus

The question of how to define consensus within Delphi study is a point of contention within the literature and highly variable across Delphi studies (Diamond et al., 2014; Hsu & Sandford, 2007). In an influential review of how Delphi studies operationalise consensus, Diamond et al. (2014) found that the most common form of definition of consensus was percent agreement (e.g. ≥80% with the same rating), with the second most common definition being a proportion of ratings falling within a range on a scale (e.g. 80% of ratings falling within two categories at either extreme on a given scale. The general trend across more recent Delphi studies (e.g. Hamilton, 2021) is to define consensus based on precedent in line with other Delphi studies in similar research areas. As such the common approach is to define consensus in terms of a proportion of ratings falling into two categories at either extreme of a scale (English et al., 2020; Hamilton, 2021; Ulschak, 1983). This definition was considered for the present study but discarded in favour of a stricter criteria of consensus of 80% or more with the same rating (i.e. ratings falling within either one of the extreme categories on a five-point Likert scale). 70% or more in either direction on the Likert scale was used to define “approaching consensus”. The approaching consensus criteria was included to aid the panel in following the consensus process and to consider their responses in light of the panel’s response.

This narrower definition of consensus was considered appropriate as it was thought that it would facilitate greater opportunities for the panel to discuss and reflect upon the guidelines, and for the guidelines to evolve and develop as part of the Delphi process. Having a broader definition of consensus runs the risk of attaining consensus before the panel has had adequate chance to revise their views and elaborate on their ratings. As such a broader definition of consensus may limit the opportunity that the panel has to develop the guidelines through qualitative comments and discussion between panellists (via comments). Although a stricter definition of consensus makes achieving consensus less likely (Fink et al., 1984), it was deemed appropriate as a means of facilitating the Delphi process (i.e., round iterations, ratings and re-ratings of guidelines, development of guideline wording through panellist comments etc). Given the stricter criteria, it was necessary to incorporate an optional fourth round, in acknowledgement that consensus may emerge at a slower rate than in Delphi studies with more inclusive definitions of consensus.

2.10 Quality criteria

Diamond et al. (2014) produced a set of quality criteria from a systematic review they completed on 100 Delphi studies. This quality criteria were used for the present study. Table 3 documents the extent to which the present study fulfils the quality criteria developed by Diamond et al. (2014).

Table 3. *Delphi Quality Criteria (Diamond et al., 2014)*

Criteria	Evidence in the present study
Study objective	
Does the Delphi study aim to address consensus?	Yes

Is the objective of the Delphi study to present results (e.g. a list of statements) reflecting the consensus of the group, or does the study aim to merely quantify the level of agreement?	The panel were required to determine which guidelines were essential and should be endorsed in the final set.
Participants	
How will participants be selected or excluded?	Inclusion criteria MDT: • A minimum of 1 year's clinical experience in a role that includes working with autistic people with intellectual disabilities in assessment and treatment units (ATUs). • Professionals with clinical experience in a role that included working with autistic people with intellectual disabilities in ATUs but who have left their role within the last year. • Inclusion criteria parents and carers: any carer or parent who has an autistic family member who has been in or is currently in LTS. Exclusion criteria: • MDT members who work with autistic people in LTS in forensic inpatient units. This is because the population in LTS in forensic units are different from those in assessment and treatment units (ATUs).

	• MDT members and carer/adult parents in Wales and Scotland due to specific legislation.
Definition of consensus	
How will consensus be defined?	80% or more agreement that an item is essential. 70% or more for approaching consensus.
If applicable, what threshold value will be required for the Delphi to be stopped based on the achievement of consensus?	N/A
What criteria will be used to determine when to stop the Delphi in the absence of consensus?	The Delphi will be stopped after a maximum of four rounds.
Delphi process	
Were items dropped?	Yes, after the final round
What criteria will be used to determine which items to drop?	If there is no consensus that the item is essential, or if consensus is reached that the item is not important.
What criteria will be used to determine when to stop the Delphi process or will the Delphi be run for a specific number of rounds only?	A maximum of four Delphi rounds were predetermined for the study.

3 Extended Results

3.1 Role-based demographic information

Information regarding the panellist's professional role, geographical location, and number of years in their role were collected at the start of each interview. The panellists were all professionals working in MDTs within assessment and treatment units for people with intellectual disabilities and autism in NHS Trusts. A total of six NHS Trusts were represented by professionals on the panel. Just over half (eight) of the panel were made up of NHS staff from one NHS Trust. This was to be expected as active recruitment was pursued at a specific NHS site and snowball sampling was used. The Panel was heterogeneous in terms of job title, which was intended to represent the diverse viewpoints within an NHS MDT. The panel consisted of two healthcare assistants (HCAs), two Clinical Nurse Specialists, two Clinical Psychologists, two Psychiatrists, two Nurses, two Occupational Therapists, one Ward Manager and one Speech and Language Therapist. No parents/carers of autistic people were able to be recruited into the study. Attempts were made to recruit parents and carers through advertising the study through the LD Senate, the

Restraint Reduction Network, and the Challenging Behaviour Foundation. However, no parents/carers came forward to take part.

The panellists' years of experience ranged from one year and three months to 33 years, and all experience was working within and NHS context. Panellists were also asked if they had experience of working with autistic people in LTS, in order to determine the context of their clinical experience. All panellists had direct experience in working with autistic people in an LTS context.

3.2 Guideline creation

Interviews ended with the generation of 3 recommendations (guidelines) by each panellist. No analysis was completed of the interviews as this is not consistent with Delphi methodology (Hamilton, 2021). Furthermore, to reduce researcher bias, guidelines were presented in the round one (Appendix M) survey in the panellist's own language, with only grammar or wording being changed to ensure that the guidelines were grammatically correct. Otherwise, the guidelines were spoken by the panellists and crafted at the end of interviews with support from the researcher. To ease the burden of panellists in navigating the survey, the items were divided into two broad categories within the survey (i.e. "Direct LTS Care Guidelines" and "Wider Service Setting Around LTS Care"), based on the semantic meaning of the items. Panellists were given the opportunity to comment on the structure of the guidelines within the survey rounds. See Table 4 below for the interview round data.

Table 4. *Results of the interview round*

Panellist No	Guideline	Interview quote
1	Improving understanding of long-term segregation and its application practically. This can be done with the use of case examples.	00:54: 32 Improving understanding of long-term segregation and its application practically. This can be done with the use of case examples. Because we've got a definition of what LTS is from CQC, which can be very subjective, you know moving around freely in an acute assessment and treatment service, what does that mean? So does that mean because you are restricting somebody with 2 to 1, but still, they are accessing the communal area, so is that LTS because they are not moving around freely? So I think more practical guidance about what LTS looks like on the ground, illustrated with some case examples.
	Staff training on the concept of LTS: what it is, why it is used, what are we looking for here, what is the aim? That needs to be more widely incorporated.	00:57:49 Training on the concept of LTS and OK, there is a risk that's why they are in LTS, but the aim of LTS is to bring them out and to bring them out this is a process that has to happen. It's not easy for staff directly working with somebody who is quite challenging to deliver that and there can be staff that do withdraw, and there are staff that come onto shift and say "I don't want to work with that person". So staff training regarding LTS, what it is, why it is, what are we looking for here, what is the ultimate aim? That needs to be more widely incorporated.
	Regular reviews, dynamic risk assessment, and	01:04:38 Regular reviews and evaluating the risk management plan and regularly updating it. And when the risk is deemed significantly reduced in

	evaluating the risk management plan and regularly updating it. When the risk is deemed significantly reduced in terms of risk to others, looking at bringing the person out. Getting staff to manage the other patients. Agreeing with the MDT at which point. Finding the appropriate time. Putting a plan together.	terms of risk to others…and often the clinical presentation especially in autism, it fluctuates, so you can never say "So he's been fine for a week and he's going to stay fine". So dynamic risk assessment. So he's been settled for two days now so let's look at bringing him out. And maybe getting staff ready to manage the other patients. And agreeing with the MDT at which point. He hasn't had incidents for four weeks, let's start discussing this. Finding the appropriate time. Putting a plan together.
2	Ensuring the use of LTS is individualised to suit their needs. It's got to fit that individual.	00:57: 30 So I've kind of said like, you know, ensuring that LTS is individualised to suit that person's needs. Yeah. 00:57:41 And I think it definitely, I mean it's, you know, it's gotta fit, it's gotta git that individual. Ensuring the use of LTS is individualised to suit their needs. It's gotta fit that individual.
	LTS always seems so cold. Making the	00:58:36 LTS seems cold, so making the environment more nurturing and you know it needs to be more therapeutic, making it more therapeutic but

	environment more nurturing. It needs to be a bit more therapeutic. It's got to be therapeutic but safe. Even just calming. The rooms lack warmth. And sometimes it does not adequately respect their dignity.	safe and even just calming, cause the rooms lack warmth and sometimes it doesn't adequately respect their dignity.
	Valuing the person. Treating them with respect, giving them choices. That can be overlooked and you're making the choices for them. Just a simple choice like "Do you want ice-cream or do you want jelly?" Just simple choices mean so much. And it can	01:01:50 Yeah, you know, it's you wanna be treated as human, don't you? You know, you don't want to be treated as something in a room. 01:02:13 Actually valuing the person you know. But you know, valuing them. 01:02:26 You are treating them with respect and giving them choices. You know and I think sometimes perhaps they can be overlooked you know? And like the fact that actually you, you know, you're making the choices for them when it actually you know. But you know just a simple choice you know? Do you want ice cream, do you want jelly? 01:03:39 Just some simple things can mean so much. Yeah and it can be so validating to somebody you know.

	be so validating to somebody.	
3	Regular reflective practice discussion specific to LTS and restrictive practice, prioritising nursing colleagues and focusing on barriers to change. Making them moral agents and helping them reflect, so that they don't become anaesthetised to the controversy, you know, long term segregation.	00:50:04 Regular reflective practice. Discussions specific to long term segregation and restrictive practices. 00:50:25 Yeah all, all. Well, certainly all nursing colleagues. 00:51:05 Prioritising nursing colleagues, and I'd say very much focus on barriers to change. 00:50:15: And making them moral agents if you like, you know, helping them to reflect on so they're never anaesthetised to the controversy, you know, long term segregation. To institutionalised practices, if that makes sense
	Long-term segregation should be regularly reviewed by the MDT and nursing.	00:55:01 So should be regularly reviewed by the MDT and nursing. This is one of the guidelines so in a way I'm only parroting what already exists. But if it didn't exist that's what I'd be saying.

	Better resourced and better hospital environments made available to people with intellectual disabilities and autism. So that we're not forced to make decisions to move people into long-term segregation. So these are actually better therapeutic environments for people to spend time in. It's not bedrooms, communal areas, or seclusion and long-term segregation. You know… that there are other options available. For someone to be able to access other space with staff only, and where	00:57:01 So better resourced and better hospital environments made available to people with LD and autism, so staff were not forced to make decisions to use LTS. 00:57:28 You know, it's not sort of bedrooms, communal areas, or seclusion and long term segregation, you know that there are other options available. 00:57:42 For someone to be able to access other space with staff only. No others and where there's space for maybe staff to be with people. not necessarily close to them. So it's less intrusive for the person who is wanting to isolate themselves 00:58:29 More spacious, varied therapeutic environments so there are other options in between communal living and LTS.

	there's space for maybe staff to be with people. Not necessarily close to them. Umm, so it's less intrusive for the person who's wanting to isolate themselves. More spacious and varied therapeutic environments. And varied, in between communal living and long-term segregation.	
4	Staff being involved in the developanellistent of the LTS and stepdown plan, so right at the onset, they know what's expected. Staff on the ground, healthcare assistants (HCAs) and support	00:42:35 Yes, Staff being involved in the developanellistent of the LTS and stepdown plan, so right from the onset, they understand what their expectation is. 00:42:47 when I say staff, I mean staff on the ground. 00:43:31 Do you mean like healthcare assistants and support workers? 00:43:37 Yeah. 00:43:41 and I think that helps them as well because they sometimes feel that decisions are made that are totally outside of. You know that they're not involved in any of the conversations.

	workers. That helps them as well.	
	The training of staff on autism specifically, but then ensuring there are reflective spaces to support staff to continue with that reflection on training afterwards.	00:45:28 I think there's definitely a training that's required around autism specifically. 00:45:52 Sometimes you can so as much training as you want, but if staff are unable to be reflective practitioners, which I've seen a lot of, they really find it difficult to then, you know, take that training away and implement it in the environment. 00:47:10 So it's about how we support staff to continue with that reflection on that training. So spaces for them to be able to have those conversations. 00:47:27 So maybe it's about training of staff, but then having spaces for them to reflect on that training. 00:48:10 Ensuring there are reflective spaces for staff to reflect on that training afterwards.
5	Making sure there is a good formulation of the person's needs so the whole support context, including environment, is tailored to those needs. There's an idea that a	00:48:16 I think there's an idea in some areas that a homely environment is a meaningful generic concept. I don't actually think it is. I think it's what's the home environment for this person? Some people like massive multi-coloured stuff everywhere, whereas others like everything to be white. 00:48:30 It's really tapping into an individuals needs and desires in that way. So sometimes you need to make the environment more homely perhaps in

	homely environment is a meaningful generic concept when I don’t think it is, it’s what’s a homely environment for this person? Some people like massive multi-coloured stuff, whereas others like white everything. So, it’s really tapping into the individuals needs and desires that way. Really tapping into the whole context for the person	a traditional sense, and other times you need to make it more homely for the person. 00:48:47 So really really tapping into the whole context for the person 00:53:39 Yeah, making that there is a really good formulation of the person’s needs so that the whole support context is tailored to those needs.
	Understanding how LTS can be a supportive context and shouldn’t always been seen as a context that should end as soon as possible. Or the end as soon as	00:50:27 Understanding how LTS the proper language being used so that we can understand how LTS can be a supportive context and shouldn’t always be seen as a context that should end as soon as possible. For all that, the end as soon as possible in terms of a hospital should be the person being provided with an appropriate community placement. Which you know I’m very very supportive of, but, but it’s interpreted as the person

	possible in a hospital, should be the person being provided with an appropriate community placement. But it's interpreted as the person must mix in the general ward, so I think moving things on from that thinking.	must be mixing on the general ward. So I think moving things on that thinking.
	Really robust review: processes that enable ATUs to support each other to complete robust reviews of people in LTS. Seeking a second opinion that challenges the decisions we have made.	00:54:35 We could come up with some processes where ATUs are more able to support each other to do really robust reviews of people in LTS. 00:54:49 Something that would be really helpful, I think that, I think it'll be a good challenge, I think we should be challenged and I think that would be a really good challenge to have a second opinion.
6	Regular reflective practice. Thinking about how LTS is working and	00:56:21 Probably is having that regular reflective practice. So thinking about, space to think about how it is working and to have other people from

	to have other people from the MDT and other staff reflect on whether that approach is appropriate. So there are open discussions.	the MDT and other staff to reflect on whether that approach is appropriate. So there's open discussions.
	Holding in mind what the purpose of the LTS and the purpose of the admission is. Thinking that this person needs to be discharged eventually. Having a plan about how we are going to get there.	00:56:57 Holding in mind what the purpose of the LTS is and the purpose of the admission. 00:57:18 So thinking about that this person needs to be discharged eventually so having that plan about how will we get there.
	Graded approach to coming out of LTS. Starting off with small changes and thinking about what might be meaningful to the patient. If there are issues like	00:57:44 A graded approach to coming out of LTS. 00:58:11 Starting off with small changes to it. I'm thinking about what might be meaningful to the other person, to the patient. 00:58:27 And if there's issues like noise or sound, is there any changes that can be made to the environment that would reduce the impact of that without using LTS?

	noise or sound, are there any changes that could be made to the environment that would reduce the impact of that without using LTS?	
7	Being clear about why you're using LTS, but also being clear on whether it is the least restrictive and most appropriate option for that person at that time. And coming back to and reminding yourself of why LTS was started. Is it working? And then thinking about what needs to happen next. A continual review process starting with why we made this decision, what	00:53:45 Being clear about why are using it. But also is that the least restrictive and the most appropriate option for that individual at that time? And I think if you have that clarity, sometimes you kinda have that clarity but it'd be to be reminded of it. 00:57:30 So coming back to and reminding yourself of why LTS was started and asking like it is working and thinking about what, what needs to happen next. 00:57:44 The continual review process, and I suppose as part of any continual review process you start with, umm, why did we make this decision? What are we looking to achieve? So that's the starting point for each review.

	are we looking to achieve. So that's a starting point for each review.	
	Personalised care but truly being creative about that personalisation makes it sometimes outside of what you would consider to be normal practice. Truly personalising every element of their experience to make it right for them.	01:01:27 Personalised care but truly being creative about that personalisation that makes it sometimes outside of what you would consider to be, what you would consider to be normal practice, you know. 01:02:45 Truly personalising every element of their experience to make it right for them.
	An awareness for staff of the impact that the individual can experience by making the decision to use LTS. It doesn't mean that it is the wrong decision, but you may	01:08:02 An awareness for staff of the impact that the individual can experience by making the decision to use LTS. It doesn't mean that it is the wrong decision, but you may have to work especially hard when you recognise the negative impact for the individual on the decision you made to initiate long term segregation. Once you're aware of that, then it opens up an opportunity to think about how the person might be feeling, what are the signals that we may be inadvertently showing them and telling them by the

	have to work especially hard when you recognise the negative impact for the individual on the decision you made to initiate long term segregation. Once you're aware of that, then it opens up an opportunity to think about how the person might be feeling, what are the signals that we may be inadvertently showing them and telling them by the initiation of long-term segregation? Therefore, what can we do to address it? What we don’t want to do is reinforce any previous trauma or attachment	initiation of long-term segregation? Therefore, what can we do to address it? What we don’t want to do is reinforce any previous trauma or attachment issues, or feelings of self-worth or disappointment that people have already experienced. We don’t need to think about all of these at the forefront of care on a daily basis. But I think we need to think more carefully about it once we've initiated long-term segregation because of the triggers and because of the signals that we’re inadvertently giving to people simply by saying you're separate, you can't mix.

	issues, or feelings of self-worth or disappointment that people have already experienced. We don’t need to think about all of these at the forefront of care on a daily basis. But I think we need to think more carefully about it once we've initiated long-term segregation because of the triggers and because of the signals that we’re inadvertently giving to people simply by saying you're separate, you can't mix.	
8	Robust formulation as to why LTS setup is beneficial for that person. Not because it’s going to	00:57:05 So you kind of want you want a really robust formulation as to why an LTS sort of set up is gonna be beneficial for that person not because ot’s gonna be easier to manage than on the main unit. Like what does that formulation look like? What’s the aim, what are you looking for and then

	be easier to manage than on the main unit. What's the aim? What are you looking for? And how do you break it down? Including having a clear idea of what it would be like to stop LTS and how you're going to get there.	how to do you break it down and I think it's really important that staff don't feel like cause that's a lot if you're working.
	Visual representation for the person, that they can input into about what their pathway out needs to look like.	00:58:07 Having a visual representation for the person that they can input into about what their journey should look like, what they need to do.
	The importance of engagement and relationship building. Critical nature of being able to form a relationship with someone at that point in their life (in LTS),	01:00:38 Yeah, the absolute kind of critical nature of being able to form a relationship with someone in, in, at that point in their life, because that makes a massive difference.

	because that makes a massive difference	
9	Good communication- making sure you know how that person communicates. Because sometimes you're behind a door and the only thing you can do with that person is communicate. So, make sure you're communicating effectively to their needs, not just thinking "Oh yeah they'll understand that" and they won't.	01:03:04 Good communication is one way to be sure you know how that person communicates. Because sometimes you're behind a door and the only you can do with that person is communicate. You can't be in there. So make sure you're communicating effectively to their needs, not just thinking oh yeah they'll understand that and they won't.
	Make sure there is a clear timeframe of what's going to happen when. So, with the step-down plan, when are we starting the step-	01:03:42 Make sure there is a clear timeframe of what's going to happen when. So, with the step-down plan, when are we starting the step-down plan? When is the next stage of this step-down plan? Because from experience sometimes we get handed a step-down plan and it's like "it's happening tomorrow" and we're like "what?", we don't even know what the

	down plan? When is the next stage of this step-down plan?	step-down plan is ourselves, and now we've got to read it in 24 hours to start it in 24 hours. So effective time of if they are stepping down, when they are stepping down, staff have enough time to know the step-down plan efficiently, not just 24 hours of rushing round. So effective time use of long-term segregation
	Making sure everyone is involved in how it's begun, so it's a team decision. Making sure everyone is on the same page so there's a plan to get someone to long-term segregation, so it doesn't turn into a messy restraint because then that's putting that room in a traumatic situation and that's not going to be a safe area because you've restrained them in that safe area.	01:05:57 So making sure everyone's involved in how it's performed so it's a team decision. Because like I say it's a team decision and in fact that they all ask us what the behaviours are and things, but sometimes they just plonk this idea of long-term segregation on us and we're like "huh? Wait wait what?". Nobody new. So, working as a team. You are all in it together whether you like it or not, everyone is contributing a factor to this person being in long-term segregation so if we're not going to work together this isn't going to work either. Making sure everyone is on the same page so there's a plan to get someone to long-term segregation, so it doesn't turn into a messy restraint because then that's putting that room in a traumatic situation and that's not going to be a safe area because you've restrained them in that safe area.

10	A better equipped and designed low stimulus environment. It needs to have the opportunity of being locked down and changed so that people can go in and deliver a certain quality of care. By having separate rooms within LTS, you can have a day room so that you can go in and make sure the bedroom is clean ready for them to sleep; then you can have a lounge area that can be cleaned if that's where the dining table is and if that is where the activities are going to be based you can gear that up ready.	00:58:10 So I think the LTS suite needs to be, it needs to have the opportunity to be locked down and changed. So that people can go in and deliver a certain quality of care. 00:58:31 So what I mean is by having separate rooms, with LTS means that we can have like a day room, so therefore we can make sure that the bedroom is clean, the bed is made, you know that, that, the bedroom is ready for them to sleep to rest you know. 0058:49 Then you can have a lounge area where that can also be cleaned if that’s where the dining table is you know if that’s where the activities are going to be based you can gear that up ready. 00:59:51 A better equipped low stimulus environment. 01:00:35 It needs to have the opportunity to be kind of locked down and changed. So it can be kind of cleaned and kind of you can have different rooms.

	To produce a document which provides staff information on how to deliver tailored and holistic care for a patient in LTS. This could include recording capacity, recording therapeutic interactions, recording interactions that didn't benefit the patient or which they reacted negatively towards.	01:04:41 So to produce a document yeah, which provides staff with information on how to deliver holistic care for a patient in LTS. Tailored and holistic to the patient. 01:05:24 Listing kind of what capacities they have, so you could say they don't have capacity in this sense, but they do in this yeah. 01:05:35 Um, recording capacity, therapeutic interactions, recording interactions that didn't benefit the patient, or that they reacted negatively towards.
	To provide staff training in intensive interaction to benefit patients who reside in LTS. By intensive interaction I mean being able to engage at a holistic level	01:10:21 To provide staff training in intensive interaction training to benefit the patient who resides in LTS. 01:11:26 By intensive interaction I mean being able to engage at the level in ways that they can benefit from. 01:12:04 Engage at a holistic level to benefit the person in long term segregation.

	to benefit the person in long-term segregation.	
11	You need to make probably more focused plans on what that physical environment will look like if you put them in there. You know, do you need so many personal items? Do you need an OT to do a sensory assessment in relation to that person? Sensory needs and adaptation before they go in. So there is more of a focus on the physical environment itself, not just accepting that it is what it is, and we've put them in	00:57:55 Environment. Environment. So again, current policy is very restrictive in terms of what you can put in, how you can put in. So the physical environment. And a caveat of actually autistic people rely on it differently, respond to it differently. So therefore you need to make probably more focused plans on what that physical environment will look like if you put them in there. You know, do you need so many personal items? Do you need an OT to do a sensory assessment in relation to that person? Sensory needs and adaptation before they go in. So the physical given more of a focus on the physical environment itself, not just accepting that it is what it is, and we've put them in there cuz it's risky and that's how it's staying

	there because it's risky and that's how it's staying.	
	Clearer communication and adaptable communication, breaking down the process of LTS in terms of starting it, going through it, and finishing it: 'This is what you need to do. This is the period of time. What it looks like on a time timer. And this is the consequence or action. This is what you're going to get from that step'.	00:59:14 Because when I was on [unit], I made you know, steps that were just very SLT approved: This is what you need to do. This is the period of time. What it looks like on a time timer. And this is the consequence or action. This is what you're gonna get from that step. 00:59:47 So clearer communication and adaptable communication. Broken down, making sure it's accessible so not just present but accessible.
	Cultural re-education: ensure that staff teams are aware of the autism, but also awareness of its presentation. So that they	01:00:04 Now you know a cultural re-education. 01:03:02 ensuring that staff teams are aware of what autism is but of it's presentation so that they don't, they don't fall into sort of what would you say, don't follow a standard LTS. They don't fall into standardised neurotypical practices.

	don’t fall into standardised neurotypical practices.	
12	Exposure to other units and other practices. Learning from other units. Because a potential issue is isolation and developanellistent of insular culture. Fundamentally openness so staff can talk to other staff in other units	00:57:33 Exposure to other units and other practices learning from other units because of the potential issues is that there’s isolation and people can develop a sort of insular culture in organisation. 00:58:51 Fundamentally, openness. So you know, OK, your staff can then talk to other staff in another unit.
	Regular review in the team and having Commissioners coming into regular ward rounds and CPAs, as they have local knowledge as well as authority to commission services.	01:02:23 Commissioners coming into regular ward rounds and CPAs. I think that's probably more relevant and helpful than indeed in my experience having CTRs because again for the same reason the CTR panel does not know the area, they do not often know the local resources, whereas Commissioners have local knowledge, as well as authority to commission services. Regular reviews including Commissioners. 01:02:57 Regular reviews in the team but reviews including commissioners.

	Reflective practice groups are good practice, where staff can speak freely.	01:03:15 I think we have a reflective practice group in our unit. Which is run by a psychologist, who's not directly involved in the unit, but another part of the trust. And I think that helps as well in terms of good practice, because patient staff can speak freely there and some of the psychological issues, which are quite often unspoken. Umm, which nonetheless have a significant impact on the way people behave, can be managed and this is looking after people
13	A graded step-by-step plan of how we support someone out, to reduce the risk of someone just living in LTS, and that becoming the new status quo.	00:49:32 So I think a graded, step-by-step graded thing of how we support someone out. 00:49:40 To, to reduce the risk of someone's living in it and becoming the new status quo.
	Ensure all staff know LTS is a short-term situation and that it's not a long-term solution.	00:53:21 So we need to be working on reducing this as soon as possible and everyone needs to be aware of that, that it's a short-term thing. 00:53:54 Yeah, that it's not a long-term solution
	Ensure a stimulating an engaging environment is	00:54:46 Ensure a stimulating an engaging environment is maintained, but it's tailored individually. Because you know when people are bored and dysregulated and locked in a building, you're just maintaining them in a

	maintained, but it's tailored individually.	certain way, not necessarily like, you know, they don't have meaningful occupation. They're not engaged, they're not stimulated
14	Develop a brief accessible overview of the person, including likes and dislikes, what makes them happy and not happy, and what stage of the step-down plan they are on. You have to keep it basic for example "Patient A is happy when they are doing X". And it must be straight to hand because otherwise it can get lost. Don't lose this basic information. And making sure the staffing team are not just seeing it as a piece of paper, it's an important part of the	01:05:39 You have to keep it basic, you got to keep it basic. You know, patient A's happy when they do this, or that, you know. 01:06:29 OK, so like brief, straight to hand kind of document that everyone can read and understand about that person. 01:07:47 You've gotta have the stage in which they're on. 01:08:02 Just making sure that they're not just seeing it as a piece of paper or anything like that. It's an important part of the structure of segregation. 01:08:13 Primarily you are focusing on ideally trying to keep that patient, individual happy. Doing things they like doing and want to be doing and working towards that goal of , you know, ending LTS or realistically just giving them a good day, a positive day.

	structure of segregation. Primarily you are focusing on keeping that patient happy, doing things that they like doing, and working towards that goal of ending it (LTS), or realistically giving them a good positive day	
	Ensure the use of LTS is fully staffed. For it to be successful you need to make sure you have a shift that is fully staffed. If a shift has the correct staffing levels, the stages of the step-down plan can be implemented. Therapeutically, activities are going to take place.	01:09:13 Ensuring it's fully supported staffing-wise and you know like I said for it to be a successful unit, it needs to have say like you need to make sure that you've got a shift that's fully staffed. 01:09:30 I know I'm living in an ideal, idealistic world, but I know that if I've got a shift that's full of the correct staffing levels that, I'm going to be able to follow or have implemented the stages of the step down plan. Therapeutic activities are gonna take place, positive interactions are gonna take place

	Positive interactions are going to take place.	
	The involvement of family. Keeping them up to date. Being open and transparent where things are difficult and being able to admit to that when encountering problems.	01:11:16 I suppose the involvement of family. 01:11:33 Keeping them up to date up to speed with what's happening with you know, their daughter or whatever. What is it that's taking place and you know, being open and transparent you know, where things you know, where things are difficult or have been difficult. 01:11:57 Admit to that you know we've been encountering problems with such and such.

3.3 Panel member responses across rounds

The responses of panellists across all rounds can be found in Table 5. 90% of panellists (13 of 14) responded to the Round One survey, with panellist 14 not responding. Within Round One, two panellists did not rate all items (panellist 8 and 9). Panellist 9 did not provide ratings for one Direct guideline and one Wider Service Guideline, and panellist 8 did not provide a rating for one Wider Service Guideline. 100% of remaining panellists (13 of 13) responded to Round 2. Five panellists did not rate all items (panellists 1, 4, 7, 8, and 12). Panellists 1 and 8 did not rate one Direct guideline; panellist 4 did not rate two Direct Guidelines; panellist 7 did not rate three Direct and two Wider Service guidelines; and panellist 12 did not rate two Direct and two Wider Service Guidelines. In Round three, 90% of panellists (12 of 13) responded to the survey, with panellist 5 not responding. Seven panellists did not rate all guidelines in Round three (panellists 4, 7, 8, 9, 10, 12, and 13). Panellists 9 and 10 did not rate one Direct guideline; panellist 4 did not rate one Direct and two Wider Service Guidelines; panellist 7 did not rate two Wider Service guidelines; panellist 12 did not rate one Direct and three Wider Service guidelines; panellist 13 did not rate one Direct and one Wider Service guideline; and panellist 8 did not rate seven Direct and six Wider Service Guidelines. In Round four (the final round used for feedback and to request vignette examples), 90% of the remaining panellists (11 of 12) responded to the survey. Four panellists (1, 3, 8, and 10) provided example vignettes as requested in Round four.

Table 5. *Panel member responses across rounds*

Panel Member	**Round One**	**Round Two**	**Round Three**	**Round four**
1	✓	✓	✓	✓
2	✓	✓	✓	✓
3	✓	✓	✓	✓
4	✓	✓	✓	✓
5	✓	✓		r
6	✓	✓	✓	
7	✓	✓	✓	✓
8	✓	✓	✓	✓
9	✓	✓	✓	✓
10	✓	✓	✓	✓
11	✓	✓	✓	✓
12	✓	✓	✓	✓
13	✓	✓	✓	✓
14		r	r	r
Total in % (*N*=)	90% (*N*=13)	100% (*N*=13)	90% (*N*=12)	90% (*N*=11)

3.4 Feedback across rounds

Feedback reduced across all rounds, with the largest reduction occurring between Round One and Round Two, whereas the number of total comments for Rounds Two to Four were similar. Some panellists feedback contributions per round varied considerably (for example, panellists 2, 3, 7, and 11), whereas other panellists' contributions were more consistent across rounds (for example, panellists 8, 12, and 13). Some panellist's contributions increased in the Round Four (for example, panellists 3 and 4). There was considerably less information in Round Four compared to previous rounds.

Table 6. *Number of comments made by each panel member per round.*

Panel member	Round One	Round Two	Round Three	Round Four
1	1	15	1	6
2	36	0	3	3
3	41	2	7	28
4	12	5	1	14
5	21	1	No response	No response
6	7	2	0	No response
7	29	1	8	1
8	14	5	1	10
9	32	25	9	14
10	10	15	13	8
11	31	2	10	2
12	36	38	27	13
13	8	1	10	4
14	No response	No response	No response	No response
Total	284	116	90	103

The highest number of comments in Round One were comments on the guidelines that did not specifically support or disagree with the guideline (e.g. “It needs to be a therapeutic environment, not punitive”). The second most frequent comment related to panellists being uncertain or disagreeing with part of or the whole guideline (e.g. “I disagree with this as an outright statement, as it may be a long-term solution – if it reflects community provision that best meets the needs of the autistic individual”). The frequencies of these two comments reduced across rounds. However, comments relating to wording increased across Round One, Two, and Three. This reflected the shifting focus of the panel as the guidelines developed across rounds. Concern that some guidelines were not explicitly person-centred appeared consistently throughout Round One (e.g. “Again, needs to be person-centred”). The frequency of person-centred comments reduced after introducing a caveat to panellists that would be included in the finalised guidelines, which would highlight the importance of not applying the guidelines generically, but on a case-by-case basis.

Otherwise, the frequency of comments generally reduced across rounds with notable increases in supportive comments and non-specific comments in Round Four. Comments relating to guidelines already being part of existing guidance, guidelines lacking specificity to LTS, and comments querying the scope of a guideline all reduced across rounds consistently. Comments suggesting improvements to guidelines (e.g. “Having to remain professional and being led by risks is important to relate here”), and comments highlighting overlap between guidelines (e.g. “Covered in other statements”) shifted in frequency across rounds, again reflecting the shifting focus of the panel as the guidelines developed.

There were generally very few comments involving direct communication between panellists across rounds, with five in Round Two and seven in Round Three. These comments either directly linked to a specific comment of another panellist, or more generally linked to panellists’ comments as shown below a given guideline. There was a brief exchange between three panellists across Round’s Two and Three (panellists 9, 11, and 12) regarding the utility of a specific assessment tool to assess the impact of LTS on the person. Panellist 9 suggested the tool may offer a useful structure to assessment, whereas panellist 11 suggested it was too narrow an assessment tool whilst panellist 12 suggested that the proposed tool was not appropriate for autistic people with intellectual disabilities and offered another tool instead. Other comments relating to panellist comments were generally supportive (e.g. “Perhaps providing flexibility in the environment – but generally agree with the points above”).

Overall, the written feedback indicated that the panel were highly engaged throughout the process, providing much detailed feedback as new information was presented across rounds. Some panellists also commented that the changes to certain guidelines reflected their previous comments, whilst others expressed support of guidelines in response to modifications. These responses further highlighted the panels high level of engagement throughout the process.

Table 7. *Feedback and frequencies of written feedback across rounds based on main areas identified in comments.*

	Round One	**Round Two**	**Round Three**	**Round Four**
Feedback	Number of comments per type of feedback			
Supportive of guideline	25	10	5	28
Comment on guideline without explicit agreement/disagreement with guideline	122	19	7	25
Guideline already exists in other guidance	11	12	5	0
Wording	3	10	27	9
Lack of specificity to LTS	22	8	3	1
Uncertainty or disagreement with whole or part of guideline	50	24	16	9
Query scope/focus of guideline	3	0	0	0
Ensuring guideline is person-centred	16	3	2	0
Suggested improvement	8	5	8	1
Guideline lacks clarity/is vague	9	9	9	2
Overlaps with other guideline(s)	8	11	1	0
Comment on other panellist comments	0	5	7	0
Other	7	0	0	9
Vignette examples	n/a	n/a	n/a	19

3.5 Comments and modifications in Round Four

In order to reduce the risk of significant attrition which may compromise the consensus process (Flanagan et al., 2016), the research team made a decision to use the final round to member check (Birt et al., 2016) the guidelines which had reached consensus. The fourteen guidelines (eight Direct guidelines and six Wider Service guidelines) were sent to panellists with accompanying clinical vignettes that had been taken from examples of clinical practice described in the interview round and anonymised. panellists were asked to provide general feedback on the guidelines as well as clinical vignettes where necessary. It was made clear to panellists that no changes would be made following feedback on the guidelines from Round Four, with the exception of minor changes to wording if these were pointed out and if multiple panellists raised the same point. This decision was taken as there would be no way to member check guidelines following Round Four.

In the final round, panellists were also asked to vote on whether some guidelines should be combined after the research team identified them as overlapping in content. Panellists were given three such questions in the final round. All panellists who responded to the final round except one voted that the combined guidelines should replace the guidelines they were derived from.

4. Extended Discussion and Reflections

4.1 Further Exploration of the guideline categories

When looking over the final guidelines (Appendix Q) within the Direct LTS Care and Wider Service Setting sections, it became apparent that the content of the guidelines touched on many different aspects of clinical practice with autistic people. These aspects included care-planning, formulation, communication, relational processes, and facilitating choice, as well as wider systemic issues such as staffing, staff and family member involvement in the planning and utilisation of LTS, training, and reflective practice. Each of these components has a body of literature attached to them. As such the below discussion was informed by reference to some of these bodies of literature.

4.1.1 Systemic factors impacting care in Long-Term Segregation

It was interesting to note that many of the guidelines addressed the wider organisational context as it related to LTS, rather that the immediate implementation and use of LTS with autistic people. Furthermore, a selection of the guidelines pertaining to the wider organisational context achieved consensus to be included in the finalised set of guidelines. Some of the guidelines within the Wider Service Setting category can be addressed by the MDT. For example, the guideline relating to staff being involved in the development of using LTS and stepdown plan, in particular Healthcare Assistants (HCAs) and Support Workers, can be implemented by MDT members. However, other guidelines within the Wider Service Setting category, such as the guideline relating to ensuring LTS is fully staffed, the guideline relating to facilitating training of staff in autism, and the guideline emphasising the need for regular reflective practice, go beyond what many members of MDTs may have the immediate power to influence. Nonetheless panellists felt that these guidelines were essential pieces of guidance that needed to be included in the final set of guidelines.

The inclusion of guidelines that go beyond the immediate context of LTS highlight the fundamentally systemic nature of LTS within the context not only of ATUs, but also the wider NHS context. The fact that several guidelines pertaining to systemic factors were endorsed as essential may also reflect the reality that at present, the system is not functioning effectively to enable MDTs to deliver high quality care to autistic people reliably. The guidelines may therefore reflect the findings of research and recent reviews into the use of LTS with autistic people and people with intellectual disabilities (Joyce et al., 2021; CQC, 2020), which has found that systemic factors, such as inadequate staffing, inadequate training of staff, inadequate support of staff, and consistent lack of family involvement, were factors appearing to be related to poor quality care of autistic people in LTS. As such the inclusion of guidelines addressing systemic factors related to LTS with autistic people reinforces the valid concerns that many have expressed about the quality of care currently being offered to autistic people in inpatient settings (Richards, 2020; Mencap, 2019; National Autistic Society, 2017). The inclusion of Wider Service Setting guidelines may also reflect an awareness within the panel that the “problem” is not located within the autistic person, but in the systems around the person that affect the quality of care on offer.

For example, in considering the guideline that recommends regular reflective practice that is specific to LTS, this guideline specifically locates the “problem” outside of the person being cared for and outside the immediate context of LTS and implies that reflective practice is not something that is readily being facilitated by MDTs in ATUs. There is very little research on the consistency or availability of regular reflective practice in inpatient services for autistic people and people with intellectual disabilities. However, a recent review of studies examining factors associated with abuse of autistic people in inpatient services found that lack of reflective practice was an organisational risk factor associated with higher risk of abuse (Collins & Murphy, 2022). Furthermore, a recent study examining staff views of reflective practice groups (RPGs) in ATUs found that staff valued RPGs, thought they improved their care of patients, and provided a safe space to reflect on clinical issues (Green & Cappleman, 2023). The study also found that a lack of specific aims in RPGs can limit their perceived utility among staff. As such the guideline recommending reflective practice that is specifically tailored to the implementation of LTS with autistic people, as well as recommending specific issues such as barriers to change and burnout are addressed, would appear to fit very well in the current clinical context and address a key systemic issue that has implications for the care of autistic people in LTS.

Another related systemic factor impacting on the care autistic people receive in LTS relates to training that staff receive. Recent research has identified significant variability in staff training and skills related to autism specifically, with one study finding that only 46-60% of professionals possessed relevant skill sets in inpatient settings to suitably support autistic people (Jones et al., 2021). Jones et al. (2021) point out that this is likely to mean that autistic people will experience a “postcode lottery” regarding the quality of care they receive. It has been pointed out that the recent autism training developed by Health Education England (2022) may be able to fill some of the gaps in training (Burrows et al., 2023). However, at present it is unclear if e-learning packages such as the new autism training (NHS England, 2022) reliably improve professionals’ knowledge and skills (Vaona et al., 2018). Furthermore, it is not clear how e-learning translates into improvements in clinical practice, or the way professionals approach the care of autistic people.

As such, the inclusion of a guideline that recommends training in autism specifically, in the context of good practice in using LTS with autistic people, may imply that current training packages are not meeting the needs of staff in this clinical context. This may suggest that current learning packages may need to be supplemented with competency-based training, and regular access to trained professionals for staff who work the most with autistic people. This may enable staff to model ways of interacting with autistic people and thereby improve the care they provide (Joyce et et al., 2021; Jones et al., 2021).

Finally, the inclusion of a guideline explicitly stating the need to ensure that LTS is fully staffed reflects ongoing issues relating to staff shortages within inpatient care of autistic people (NHS England, 2023). Staffing shortages within ATUs has been found to lead to increased reliance on agency staff, who may not know the needs of the people they are caring for, nor are they likely to have built up a strong trusting relationship with the person. For autistic people, this can mean being cared for by staff who are not familiar with their communication needs, and their likes and dislikes (CQC, 2020). Consequently, the quality of care being offered can be diminished and autistic people can be left in LTS without interaction with other people or engaging in meaningful activities (CQC, 2020). The inclusion of a guideline recommending the need to ensure LTS is fully staffed can also be seen not so much as an autism-specific guideline but as a guideline relating to basic quality of care that any person would need in an inpatient setting, before even considering autism-specific adaptations. As such this guideline may reflect a general systemic deficiency within the current system that needs to be urgently addressed.

4.2 Inconsistent feedback contributions from panellists and the role of qualitative feedback

One of the biggest strengths of the current Delphi study was the consistency of panellist responses across rounds, with attrition rates being no higher than 7% across all rounds. However, within the panellist group there was considerable variance in terms of the quantity of qualitative feedback provided across rounds, with some panellists consistently offering comments on nearly all the guidelines across multiple rounds, whereas other panellist comments became much more infrequent as the study progressed. For example, a Clinical Psychologist provided the highest number of comments across all rounds, and consistently provided over 20 comments within each of the first three rounds. In contrast, the two Psychiatrist's and HCAs provided much fewer comments across rounds, with no comments in rounds two and three. As such the voices and professional views of certain MDT members were represented more than others. This may partly reflect the relative time constraints that certain MDT members have within an average working day in the NHS to contribute to research that asks for a significant allocation of time to engage in, with HCAs have relatively less time to allocate to research engagement than other professionals such as Clinical Psychologists. On the other hand, less frequent responses may reflect participant fatigue across rounds, as there were generally less comments in rounds two to four compared to round one. Furthermore, it may have been the case that some panellist's became disillusioned with the Delphi process and as such their interest waned over time (Yousuf, 2019). However, this does not explain the continued engagement with the rating process of the Delphi method by the majority of the original sample.

One of the intended purposes of utilising the Delphi methodology was to enable participants to contribute to the consensus building process whilst minimising the influence of perceived power/knowledge in inhibiting some panellist's from voicing their opinions (Krenz et al., 2020). It was hoped that the voices of those who work most closely with autistic people in LTS, such as nurses and HCAs, would contribute to the consensus building process with wider MDT colleagues, with their qualitative comments as well as their Likert scale ratings. As such it is possible that the inconsistent feedback contributions from the panel may have favoured certain views on caring for autistic people in LTS over other views, which in turn may have influenced the outcome of the consensus process.

There was very little in the way of direct responses to panellist comments from other panellists and exchanges between panellists in the comments section, with only one exchange between two panellists between rounds two and three. Otherwise, the panellists' comments across rounds two and three appeared to stand alone rather than necessarily reflecting a "group communication process" (Yousuf, 2019). There is at present no consensus on how to present feedback to the panel from the previous round (Meijering & Tobi, 2016), with most Delphi studies opting to present quantitative, summary statistics only (Boulkedid et al., 2011). A strength of the present Delphi study was the inclusion not only of summary statistics, but qualitative panellist feedback, the inclusion of which is rare in Delphi studies and its absence often criticised as being insufficiently informative (Rowe & Wright, 1999; Meijering & Tobi, 2016). However, the role of the qualitative feedback may have been improved if it was made clear to the panel to specifically provide rationales for their opinions, in addition to any other comments they wish to provide. This may have led to increased and consistent qualitative feedback across all rounds and from more panellists, thereby enabling the voices of more MDT members to be considered.

4.3 Implementation plan and dissemination

The first step in the dissemination process will be to submit the journal paper to the Journal of Autism and Developmental Disorders. Dissemination may also be aided by approaching groups such as the LD Senate and the Challenging Behaviour Foundation and ask if they will endorse the guidelines. This may further increase awareness of the guidelines.

In terms of implementation, it will be important to consult the implementation science literature. There are many different implementation frameworks within implementation science (Holtrop et al., 2021). Among these, the Reach, Effectiveness, Adoption, Implementation and Maintenance (RE-AIM) Framework (Glasgow et al., 1999) is one of the most used within health settings. The RE-AIM Framework consists of five dimensions that can be used to evaluate an intervention at individual and organisational levels. Furthermore, the application of the dimensions is flexible, allowing for specific dimensions to be prioritised or excluded entirely depending on the specific type of research that is being translated into practice. As such the RE-AIM Framework provides a clear strategy for implementing the guidelines and evaluating their implementation along multiple dimensions. Another strength of the RE-AIM Framework is that is it flexible with respect to the type of data that can be gathered, with scope for gathering both quantitative and qualitative data for assessment purposes (Holtrop et al., 2021). Table 8 below provides a definition of each of the RE-AIM dimensions, alongside suggestions for reporting on the implementation of the guidelines.

Table 8. *RE-AIM Dimensions and suggestions for reporting.*

RE-AIM Dimension and Definition	**Possible variables to be monitored/reported**
Reach (individual level): The absolute number, proportion, and representativeness of individuals willing to participate in an initiative, intervention, or program with reasons why or why not.	Quantitative: the numbers of MDT members making active use of the guidelines and their characteristics (e.g. HCA, Nurse, Psychiatrist etc) Qualitative: interviews could be completed to explore the motives/reasoning for staff use or non-use of the guidelines.
Effectiveness (Individual level): The impact of an intervention on relevant individual outcomes, including negative effects and broader outcomes on quality of life; variability across subgroups.	Quantitative: Could be assessed in terms of individual patient outcomes (e.g. engagement in/facilitation of meaningful/therapeutic activities; choice facilitation; family involvement etc).

	Such assessments would have to be individual tailored to the patient. Qualitative: Interviews could be conducted with staff exploring their views of the role of the guidelines in their practice.
Adoption (setting and staff levels): The absolute number, proportion, and representativeness of settings and intervention agents (people who deliver the program/intervention) who are willing to initiate a program, initiative, or intervention, and why. Adoption can have multiple levels, e.g. staff under supervision, within a system/organisation, or community.	Quantitative: Could measure the number of ATU settings that have adopted the guidelines. Qualitative: interviews could be completed to explore the specific ways that the guidelines are utilised by staff; how staff make use of the guidelines alongside other existing guidance (e.g. the MHA Code of Practice 1983).
Implementation (Multiple settings and delivery staff levels): Fidelity to the various elements of a programs/interventions/initiative's key functions or components, including consistency of delivery as intended, costs of implementation, and adaptations made to intervention/program/initiate.	Quantitative: Could measure which specific guidelines are utilised more or less often by staff and why. Measure number of adaptations to the guidelines. Qualitative: Staff and/or ATU teams/Managers could be interviewed to explore their implementation strategies for the guidelines.
Maintenance (individual and setting levels): At setting level, extent to which an initiative, program or policy becomes institutionalised/part of routine practice. At individual level, the long-term effects of a program or policy after its completion. Specific timeframes for	Quantitative: Could measure the length of time that the guidelines are informing practice after they have been introduced to an ATU/MDT. Could be assessed at 6, 12, and 24 months. What factors

assessment of maintenance will vary across projects.	enhance or diminish maintenance of guideline use? Qualitative: At individual level, staff could be interviewed to explore changes in practice following guideline introduction (e.g. increased reflective practice sessions, content of sessions etc).

Current evidence indicates that guidelines often do not translate into changes in actual clinical practice (Rauh et al., 2018). Barriers to implementation include the professional’s knowledge and attitude, guideline-related factors such as poor layout or high complexity, and external factors such as a lack of resources, organisational constraints, and social norms (Rauh et al., 2018; Fischer et al., 2016; Baiardini et al., 2009). Furthermore, it is essential that guidelines be evidence-based, plausible, applicable, and focused on a well-defined patient group (Flodgren et al., 2016). The current guidelines are derived from a practice-based evidence framework which has high external validity, making the guidelines plausible as a tool for guiding clinical practice. The guidelines are also specific in that they are focused on guiding clinical practice with autistic people in a pre-defined context (LTS in ATUs).

As such it will be important to focus on potential barriers to the implementation of the guidelines, as well factors that facilitate their implementation. A potential barrier in the implementation of the guidelines may relate to the MDT staffs existing knowledge and attitudes. For example, some of the clinical vignettes describe scenarios in which patients have spent the entirety of their stay in an ATU within LTS. This may be perceived as contradicting existing guidelines, such as the MHA Code of Practice 1983 (DoH, 2015), which is explicit in defining LTS as an intervention that should end as soon as possible, with the person being integrated into the main ward environment. This barrier may be addressed through communication about the rationale for the guidelines through educational meetings and group training sessions (Fischer et al., 2016). Such meetings will also further increase awareness of the guidelines, which has been identified as another major barrier in guideline implementation (Fischer et al., 2016). Finally, given the potential for perceived contradiction between the current guidelines and existing guidance, it may be useful to identify opinion leaders within organisations who can disseminate the guidelines within the service.

4.4 Epistemological position

The present research adopted a social constructivist position and was informed by Gabbay and Le May's (2011, 2004) work on the "mindlines" paradigm. Social constructivism refers to a theory about how knowledge develops through the interactions of individuals within historically and culturally specific contexts (Taylor, 2021). "Truth" is understood to be contingent on human perception and social experiences, and as such social constructivism understands human learning and knowledge to be the outcome of human interaction, rather than as something discovered independently of human social processes (Taylor, 2021). Although recent Delphi studies (e.g. English et al., 2020) have made use of a social *constructionist* epistemological position, the social constructivist position was deemed a more appropriate position to adopt, specifically as it focuses not only on the nature of knowledge production, but also on how humans learn within their environment. This feature of social constructivism was deemed important, as a key aim of the guidelines is to facilitate changes in clinical practice through incorporating the guidelines into current practice, which necessarily involves learning. The social constructivist paradigm also compliments Gabbay and Le May's (2004, 2011) work on the "mindlines" paradigm, which specifically refers to knowledge as learnt sequences of thoughts and behaviours that are dependent on professional interactions and the contributions individuals make in shaping the shared understanding of a specific context or reality. Furthermore, this conception of knowledge compliments the methodological approach of the Delphi method, which systematically facilitates an interaction between individuals to produce a shared understanding of a specific situation or problem (Hanafin, 2004).

In utilising the social constructivist "mindlines" paradigm (Gabbay & Le May, 2004, 2011), the present study aimed to harness the presence of clinical mindlines that the panel of experts were assumed to have brought to their engagement in the Delphi process. Because the nature of mindlines is such that they are "tacit", (Gabbay & Le

May, 2004, p.1), and therefore potentially not explicitly articulated except within specific interactions, the present Delphi study has contributed to disseminating localised “knowledge in practice” through the production of a set of explicit guidelines. Being derived from the practice of specific MDT members across varying ATU contexts, it may be the case that the guidelines have a level of external validity that mean they may be more likely to reflect similar tacit mindlines in other ATU contexts and MDTs. This in turn may increase the likelihood of adopting the guidelines or making beneficial changes to the practice of caring for an autistic person in LTS. Furthermore, Gabbay and Le May (2011) point out the power that narrative has on transmitting and sharing clinical knowledge, which can be a powerful learning aid (Cox, 2001). The inclusion of the clinical vignettes to illustrate the guidelines may therefore provide a powerful means for generating new learning and translating the guidelines into practical changes in clinical practice.

It is also important to acknowledge some of the limitations of adopting a social constructivist epistemological position for this research. Firstly, in accepting that “knowledge” is not something universal but instead a product of human interactions within specific contexts, there is a definite limit to what can be inferred from the study’s findings. The findings can be said to reflect aspects of MDT members mindlines from their specific practice context, and as such they may have limited applicability to other contexts, even other ATU contexts. There is also potentially a risk in making tacit guidelines into explicit, written guidelines, in that written guidelines were precisely what Gabbay and Le May (2004) found professionals to generally not consult. However, this risk may be countered by ensuring that the implementation of the guidelines is evaluated following an implementation framework such the RE-AIM Framework suggested above (Holtrop et al., 2021).

4.5 Future research

4.5.1 Utilisation of the guidelines

Alongside applying an implementation framework to effectively implement the guidelines, it will also be important to examine specifically how the guidelines are utilised in practice by MDTs. The significant insight of Gabbay and Le May (2004) was that often, clinicians rarely consulted formal sources and research, except in cases that they found to be particularly challenging. More often the practice of clinicians was shaped by brief reading, but mainly through interactions with others (Gabbay & Le May, 2004). Gabbay and Le May (2004) acknowledge that their model was derived from a specific working context and that other contexts may differ in terms of how knowledge is put into practice. The ATU context and organisational structure may influence how knowledge (including the guidelines) is turned into “knowledge in practice”. Longitudinal, ethnographic research may be useful in following how the guidelines are utilised within ATU contexts, through the use of non-participant observation and informal interviews (Gabbay & Le May, 2004). Furthermore, given that the guidelines were derived from expert opinion following the mindlines paradigm, it will be interesting to examine if these guidelines are more readily taken up by MDTs than other types of guidelines.

Finally, it is likely that the clinical practice of using LTS with people being cared for in ATUs will present a significant challenge to the values of some MDT members who are asked to implement LTS. Recent research has suggested that the use of restrictive practices and coercion in care was associated with moral injury, defined as psychological distress characterised by feelings of guilt and shame, that arise because of witnessing, perpetrating, or failing to prevent an act that contradicts a person’s moral values (Webb et al., 2023). Given Gabbay and Le May’s (2011) finding that formal sources are more likely to be consulted in challenging clinical contexts, it may be the case that MDTs will readily value specific guidance derived from MDTs working in similar contexts, to help guide their own collective decision-making around how best to care for an autistic person in LTS.

4.5.2 Divergent views of the use of LTS with autistic people

Among the panel across the rounds, there were a range of views that expressed how LTS ought to be utilised with autistic people. some MDT members firmly held to the view that LTS should never be used without an active plan to end its use as soon as possible, a view consistent with current guidance (i.e. the MHA Code of Practice, 1983). However other MDT members were clear in articulating a view that LTS should be seen not as something that necessarily needs to end as soon as possible, rather that the decision to end LTS should be one made based on the individuals needs at the time. As such there were contradictory views held by the panel on how

LTS should be utilised with autistic people. This conflict may be a barrier to implementing LTS good practice guidelines that may be important to be aware of when attempting to implement the guidelines.

4.6 Critical reflections

4.6.1. Decisions

The Delphi method is flexible enough to allow it to be applied to a wide range of issues. One of the potential problems with this flexibility however is a lack of consensus around some of the key decisions that need to be made when implementing a Delphi study. As such there were several decision points that needed to be carefully thought out by the research team, to minimise bias and justify the decisions made (Donohoe & Needham, 2009).

One key decision point related to how to extract the data from the interview round for the survey. Often, transcripts from interviews are analysed using thematic analysis (Brady, 2015; Thangaratinam & Redman, 2005) to derive the survey items. There were a couple of reasons why for the present study this decision was not taken. Firstly, the study aimed to develop a set of good practice guidelines that could be accompanied by clinical vignettes. As such we wanted the guidelines to be linked as clearly as possible to the vignettes that were derived from the descriptions of clinical practice given by panellists. Therefore, qualitative analysis of the proposed guidelines given at the end of interviews may have created a level of abstraction within the guidelines that would have minimised their relationship to the concrete examples given in the clinical vignettes, in turn negatively affecting their external validity. Secondly, we wanted to keep the guidelines in their original wording as this was more faithful to the “mindlines” concept (Gabbay & Le May, 2004) of sharing “knowledge in practice”, which in practice is not filtered through qualitative analysis, but shared between individuals. Therefore, consistent with previous Delphi research which aimed to develop good practice guidelines (English et al., 2020; Wells, 2021), we used first order constructs (i.e. the panellists original wording) when deriving the survey items (Malpass et al., 2009).

There were also several decisions to made in relation to modifying and/or removing survey items in response to panellist feedback. In some Delphi research it has been judged as appropriate to remove items between the Round Two and Three surveys if they have not reached consensus (Berk et al., 2011). This may help to reduce the burden on panellists and thereby reduce attrition. However, there is a risk that consensus would be forced by removing items that had yet to reach a consensus (English et al., 2020). Furthermore, because this was the first Delphi to focus on this specific clinical context, and because the area is controversial with a range of sometimes contradictory opinions, it was thought important that panellists have access to all the data in each survey round, including guidelines that had yet to reach consensus, as this would maximise the opportunity to develop and refine the final guidelines in an organic way. Therefore, no items were removed between Rounds Two and Three.

There is no current agreement on how guidelines should be modified between rounds, and as such this was discussed in detail between the primary research and the second and third researchers. A distinction was made between minor and major modifications, with minor modifications denoting changes to wording that otherwise did not affect the meaning of the guideline. Major modifications denoted rewording of the guideline. The intention behind modifications was to incorporate as much of the panellists' suggestions as possible, in instances where two or more panellists made similar comments or suggestions, reflecting their qualitative feedback and therefore facilitating the refinement of the guidelines. However, it will be inevitable that the primary researchers own subjective interpretation of the comments and suggestions will have had some influence on the modification process, possibly introducing some bias. This should have been mitigated somewhat by the involvement of the second and third researcher, both of whom have clinical experience in the area of the study.

Furthermore, the decision to set consensus levels a priori will have further mitigated researcher bias in the Delphi process. However, it is also important to note that setting the consensus level within Delphi studies is somewhat arbitrary. Whilst previous Delphi studies (e.g. Hamilton, 2021) drew upon similar studies to determine their consensus level, there were no studies identified in the Delphi literature that could be drawn upon when determining consensus levels in the present study. Within the extant Delphi literature, consensus levels have been determined based on the extent to which areas have been researched, or based on the homogeneity of the sample, with higher consensus levels being preferred in areas that have previously been researched or for samples that are more homogeneous (English et al., 2020; Rayens & Hahn, 2000). In the present study, although the sample was fairly heterogenous in terms of MDT profession (potentially justifying a lower level of consensus threshold), it was thought that a higher level (80% or more) would be appropriate, and specifically with agreement falling in either end of the Likert scale, rather than the two categories at either end of the scale. This last decision was important, as allowing consensus levels to be captured within the two extremes at either end (i.e. “important” and “essential”), thus creating a broader definition of consensus, may have limited the consensus building process.

The flexibility of the Delphi method is a strength, and it particularly compliments research that is couched in a social constructivist, PBE approach (Guzys et al., 2015; Hanafin, 2004). However, the flexibility of the Delphi method did at times result in uncertainty about how to proceed with certain key decisions, such as how to define modifications and how to determine consensus levels. It was at these moments that regular contact and discussion with the research supervisors that enabled the primary researcher to think critically about the decisions made and thereby uphold the rigor of the Delphi process.

4.6.2 Co-constructive nature of the guidelines

In keeping with the social constructivist underpinnings of the present research, it is appropriate to critically reflect on the actual processes involved in the emergence and development of the guidelines, such as the process of deriving the guidelines in the interview phase.

Firstly, whilst the wording of the guidelines within the first survey were not altered in any way, to maintain consistency with the panellist’s own words, it is worth noting how the actual process of wording the guidelines inevitably involved some participation of the primary researcher on some occasions. Sometimes participants would provide lengthy descriptions of clinical practice, within which were contained statements that when clarified by the primary researcher through questioning, emerged as the intended guideline. On other occasions however it was necessary for the primary researcher to support panellists with wording suggestions, which they could either adopt or discard, as a means of identifying guidelines. Whilst the researcher was always careful to be explicit that it was the panellist’s choice on how the proposed guidelines were worded, there was nonetheless a process of co-construction between primary researcher and some panellists. As such it is important to be explicit about the co-constructed nature of the guidelines.

In keeping with a social constructivist epistemology (Taylor, 2021), the guidelines are therefore a construct derived from the research process and are not simply "discovered" or taken from pre-existing clinical contexts. Whilst this last point could be said to undermine the guidelines external validity, from a social constructivist perspective, the guidelines are argued to have validity as "contingent generalisations" (Lupovici, 2009), that is, as constructs which possess a limited degree of external validity contingent on their application in similar contexts, that reflect the contexts from which they were derived. This may be a subtle put important theoretical point that impacts clinical practice, in that guidelines should never be uncritically applied in practice, no matter how "valid" they appear. This last point highlights a strength of the social constructivist position, which maintains a consistent (and persistent) scepticism toward any kind of established truth or knowledge, without at the same time denying that there could ever be any valid knowledge (Cottone, 2017). Consistent scepticism may be especially important in the context of addressing the current state of mental healthcare provision and support for autistic people in the UK, which has been found to be very poor (CQC, 2021).

Furthermore, the contingent nature of the guidelines is consistent with the mindlines construct (Gabbay & Le May, 2004), which recognises the context-sensitive, socially constituted nature of knowledge, and underlines the character of the guidelines as not being "facts", but as a series of prompts (English et al., 2020) that may foster new socially constructed knowledge in context.

4.6.3 Personal reflections on the use of LTS with autistic people

During the early stages of beginning to read the literature around the topic of the use of LTS with autistic people, I soon discovered a series of social movements, such as Bringing Us Together (https://bringingustogether.org.uk/) and Rightful Lives (Rightful Lives) who highlight the failures of the current care system and aim to support people out of inappropriate inpatient settings. As such I became aware of social movements aiming to end the current system of care for autistic people and people with intellectual disabilities and put in its place a care system that puts autistic people and people with intellectual disabilities truly at the centre of their care (Richards, 2020; Aspis, 1997). I was also aware of the objections that could be raised to the rationale for the current research, for example how the notion that LTS may be a preferable environment to care for some autistic people in ATUs amounts to a forced choice, in that the main ward environment is simply not designed to meet the needs of autistic people (Quinn et al., 2023), and so the only option is a segregation room where they remain largely isolated from other people, whether they prefer this or not.

These reflections left me feeling uneasy about the positioning of the current study. I could understand the strong opposition to and desire to radically alter the current care system, which has repeatedly and continues to fail autistic people and people with intellectual disabilities (Richards, 2020). I remember bringing these reflections to my supervisor and discussing how at the time I was not sure if it made sense to me to conduct a piece of research that was pro-LTS, and I was not sure if I wanted to adopt such as position as a researcher and Clinical Psychologist. I also had concerns about whether it was even possible to significantly effect change in the context of an intervention such as LTS. I considered that the nature of an intervention like LTS, in which another human being is removed from the company of others, quite possibly when they do not want to be, and forcibly placed in a locked room on their own whilst being monitored, was an inherently dehumanising event that could not be remedied by trying to improve how it is implemented.

I continued to reflect on these concerns for some time whilst also continuing to develop the project. When I came to beginning to interview MDT members about their experiences of using LTS with autistic people and their views on its use, I began to learn more about the current place of LTS within the ATU environment. The negative impact of LTS was something that most of the MDT members within the study were aware of and acknowledged, such as for example how using LTS with someone can significantly delay their discharge into the community, and how LTS can be used sometimes because MDTs do not know how else to support someone. However, participants also saw LTS as a useful intervention, seeing it as for example an opportunity to really start to get to know the person, but that sometimes there is a risk that engagement with the person can disappear when they are placed in LTS. Another participant spoke about how the official definition of LTS in the MHA Code of

Practice 1983 (DoH, 2015) framed LTS as a negative, punitive intervention, and suggested instead that it can be use positively if used in a truly person-centred way. Participants also spoke about using LTS in a bespoke rather than generic way, creatively using LTS to replicate the living environment a person was familiar with outside of hospital as much as possible.

I found it interesting to listen to the views of the MDT members within the study as I interviewed them. I began to appreciate how some MDTs, in their use of LTS, were struggling with the current definitions of and understandings of the use of LTS, and how some MDTs were trying to find ways of making use of the space that was as therapeutic and caring as possible. However, attempts to make good use of LTS seemed to clash with some of the official as well as misunderstood views about the function of LTS that MDT members felt some of their colleagues held. In reflecting on the participants views of the use of LTS with autistic people, it occurred to me that what MDTs were struggling with was how to effectively provide care for autistic people in a care setting that is simply not built with autistic people in mind. Because of this, MDTs were having to try to make use of an intervention (LTS) in ways that clashed with “official” understandings and definitions of it use. This fits with the fact that care pathways for autistic people are clustered together with care pathways for people with intellectual disabilities (Burrows et al., 2023). However, this clustering of care pathways results in autistic people being placed into services that are not designed to effectively meet their needs.

In reflecting on this towards the end of writing up the thesis, I still feel uneasy about producing research that contributes to the maintenance of a care system that appears fundamentally disordered with regard to the specific needs of autistic people. My view of the research at the end of the thesis is that this research constitutes an attempt to make positive change within a broken system, change that may help to reduce the harm that parts of the current care system, in this instance LTS in ATUs, can cause autistic people. However, it is my view that changes within the system, such as producing guidelines to try to shift practice, are not at all sufficient for the more urgent need to radically alter the way that society sets itself up for autistic people to live well.

4.7 Reflections

This section contains general reflections on my work on the thesis at various points in time, derived from my reflective diary notes through the thesis process. It does not cover every aspect of the research process, rather it is intended to capture moments that felt important to me as a Clinical Psychologist in training.

Going into the Doctorate in Clinical Psychology, I remember being excited about the prospect of being supported to develop my research skills, and to choose a research topic that was based on what interested me. Looking back now in the present over the last three years, I have since come to appreciate the complexity of the work that goes into producing a piece of research. I have also come to appreciate the importance of balancing one's own interests, with the need to look very carefully and critically at what I am doing as a researcher, and the need to carefully evaluate my own capacities. This I came to appreciate through trying to obtain ethical approval on my original thesis project idea, which was to work with transgender people trialling a trauma-focused intervention that specifically focused on identity-related traumatic experiences, such as a gender-based hate crime or assault. My interest in this area was fuelled by my own identity as a bisexual man, and the idea of contributing to research in LGBTQ+ psychology (Moradi et al., 2009) felt significantly important to me.

Looking back now on my initial approach to the thesis, something I can appreciate more now is the importance of thinking carefully about balancing my own interests with the reality of my actual research and clinical skills. Looking back, I think I was driven more by my own interests and did not consider how difficult it may be to complete the original thesis project. Looking back now, I do not think I was ready to work with transgender people, partly because I had never worked with them before, but also because I had never done any trauma-focused work before. I also did not feel confident enough to address the ethical concerns of the NHS ethics committee expressed about the research. As such I think at the time I had perhaps stepped beyond my current abilities.

This brings me to the present thesis project. I had never developed my own interview schedule before; I had never completed semi-structured interviews before; I had never used the Delphi method before. Having to drop my first project made me acutely aware of the need to think very carefully about the decisions I was making regarding the study design, sample, and methodology. I also had to think carefully about whether the project felt feasible for me as a Trainee, and not simply because it was another interesting topic to me. Was I capable of implementing the Delphi methodology? One of the difficulties I experienced in the process of trying to develop the first thesis project was in approaching supervisors and asking questions, as I was anxious about appearing to not know something. When speaking to supervisors, they seemed to know so much, and I struggled to become part of a dialogue that I could learn from. As such I hypothesised that at the time, I was too anxious to start "learning from experience" (Bion, 1962), as for me the experience of learning did not initially feel safe, characterised as it is by uncertainty, frustration, and the risk of not knowing (Gabriel, 2019).

It has been hypothesized that in the struggle to learn something new, students in higher education may have an experience of feeling incompetent and disappointed, and therefore may become reluctant to think for themselves and learn from experience, preferring instead a "ready-made" understanding (Karagiannopoulou, 2011). This feeling of incompetence and vulnerability may be exacerbated by a tutor's own failure to appreciate the faltering attempts to understand made by students, as well as the value they place on answers reflecting their own perspective (Karagiannopoulou, 2011). In having to switch projects halfway through training, there was a sense in which I was looking for a "ready-made" or "off the shelf" project, but not just for practical reasons. Although I struggled to acknowledge it at the time, I felt like an "outsider" in relation to psychology research generally, having very little experience of research outside of my undergraduate psychology degree, and therefore little appreciation of how to identify a gap in the research literature in which to complete research. Therefore, in approaching a supervisor who could suggest a project, I was able to find a way into the research process that struck a helpful balance, enabling me to think for myself, but on the basis of a "ready-made" sketch of a research project.

Having an initial foundation in an idea for a project that had been sketched in collaboration with my primary academic supervisor for the thesis was a key moment for me to begin to start "learning from experience" (Bion, 1962), in that the sense of there being an initial idea may have functioned as a container for my own anxieties, specifically in the learning context (Gilmore & Anderson, 2016). Furthermore, given my new appreciation of the need to carefully think about whether the project was feasible for me, I was careful to look over previous Delphi projects by former trainees, which helped me to determine how I felt about what may be entailed in conducting a piece of research of this kind. Looking over the previous Delphi projects helped me to discern a general sense of what I may need to do, which further helped to contain my anxiety.

Although I had no experience of the Delphi methodology, much like I had no experience of the design and methodology within my original thesis project, I had some similar experiences that I could draw upon when thinking about conducting the Delphi project. For example, LTS was something that I had worked with when I was an HCA, so I was somewhat familiar with it as an intervention in inpatient settings, including with autistic people. Furthermore, I had recently completed a semi-structured interview as part of my small-scale research project (SSRP), so felt confident in being able to compete this part of the research. Also, my primary supervisor was also my supervisor for my SSRP, and we had developed a positive working relationship during that piece of work. On reflection the supervision for the SSRP was a crucial experience for me to be able to manage my anxiety about learning from supervisors. As such I made the decision to move forward with the project.

As the project developed, one of the first challenges was to address the ethics panel's questions in a meeting. The anticipation of this meeting was anxiety provoking for me, since in the last ethics meeting for my initial thesis project, I had felt out of my depth in being able to confidently address some of the panel's questions. As such, to prepare for the meeting, I arranged for a meeting with my primary supervisor for the project, in which we thought about the key areas of discussion that could arise in the meeting and went through some brief role plays to practice answering questions. As such I was able to make use of direct feedback which partly resembled deliberate practice (Anders Ericsson, 2008), in which the unfamiliar task of responding to ethics panel questions was being practiced and immediate feedback on performance was being received. As a learning experience, this was a very helpful meeting for me, as I was able to learn to tolerate not knowing through exposure (Carey, 2011) via the role play questions, as the context provided a safe setting for errors to occur that could be corrected. Furthermore, I think that the relational aspect of this was important for me, as previously I had not felt safe to feel perceived as not knowing, whereas in this context I was able to tolerate it. I think this was due to the quality of the supervisory relationship, and for me this highlights the importance of relational and affective processes within learning experiences (Gabriel, 2019; Gilmore & Anderson, 2016).

As the project progressed and I continued to have supervision meetings to discuss key decisions related to the project, I became aware of how I felt increasingly confident and at ease within the meetings and able to formulate my own rationales for decisions. This increasing confidence was again I believe based on experiences of learning in the relational context of supervision. For example, in having to decide how to incorporate feedback from the Round One survey into the Round Two survey, I was initially unsure how best to approach this task, and it felt daunting to think about how to effectively approach a large amount of qualitative data. Through emails and discussions with my supervisors, I was able to develop my own capacity to make judgements about this process, based on suggestions from my supervisors, which I then incorporated into my own approach in working with the data. By attempting my own incorporation of the data and again receiving feedback from supervisors on draft surveys, I was able to continually refine my abilities to manage the data effectively.

A similar process was evident to me as I progressed through completing the interviews with panellists. During the first two or three interviews, I was conscious of wanting to stick closely with the predefined questions within the interview schedule. I think this was also due to not feeling confident in knowing how to effectively conduct interviews with participants. As time went on however and I completed more interviews, and through feedback from supervisors who reviewed a recording of one of my interviews, I gained in confidence. I notice this increase in confidence as manifesting as less reliance on the interview schedule itself. Rather, I would use the interview schedule to structure the interview initially but would increasingly generate follow-up questions based on what participants were saying to me, rather than rigidly sticking to the schedule. As such I was able to generate some very interesting reflections of the topic, and multiple participants provided feedback at the end of interviews expressing how much they had enjoyed discussing and thinking about their practice. As such I was able to use the interview schedule more effectively for its intended purpose, to flexibly structure the interview but also provide space to explore the participants views and experiences.

Another key component of the Delphi method is data management, particularly the management of the quantitative data relating to the Likert scale ratings within surveys. To help myself address this part of the study, I asked a fellow trainee who was also doing a Delphi study about how they managed the data, and we arranged a meeting. This was a particularly challenging moment for me again in terms of being perceived as incompetent by others. In our first meeting, which was somewhat impromptu, I recall feeling very anxious about discussing my current thoughts on how to approach the Delphi project. I remember beginning to become so anxious that I could no longer think clearly about what I was discussing with my fellow trainee. On reflection, I approached my peer out of anxiety of not knowing how to manage the data and wanting to learn this, but in this instant my anxiety become so high I could no longer learn. This experience was a powerful learning experience for me, in that I became aware of how the meaning of learning for me seemed to be related to important social processes, such as the risk of being accepted or rejected, listened to, or ignored completely (French, 1997).

When I met the same trainee for a second time to discuss data management for the Delphi, at the end of the meeting they reflected to me that they had noticed a big change in my own capacity to have discussions with them. They noticed how at an earlier point in training, I appeared very anxious in relation to discussing the work and reflected on the previous discussion I described in the above paragraph. They said that I seemed much more relaxed and able to share my thoughts about the work and think with them about decisions relating to the research. This was something I was aware of in myself when in meeting with my supervisors, as I noticed how I was able to share my thoughts and rationales for decisions without feeling inhibited and anxious. One consequence of this decrease in anxiety was being able to make use of a peer’s knowledge and understanding of managing data within a Delphi study, which has been indispensable to my work in completing the Delphi.

In conclusion, the process of completing this research has been a significant personal journey. At the beginning of training, I was more interested in developing my therapeutic skills rather than my research skills. Now, having completed the Delphi project, as well as having gone through the entire experience of trying to develop a research project, and having to identify a new one, I feel I have gained a lot of confidence in approaching research in the future, particularly within NHS settings. I have also gained much from the experience of learning whilst completing the Doctorate. The challenges I have faced in terms of my anxiety around learning and educational settings I feel have helped me to appreciate the experience of learning, particularly as a trainee Clinical Psychologist. I am interested in teaching trainees, fand I have been invited to take part in reflective practice sessions with trainees. I feel confident that my own experiences of the relational and affective components of learning will make me a better teacher/facilitator for trainees as I move forward in my career as a Clinical Psychologist. Finally, I have come to appreciate that my work as a researcher needs to be balanced by, on the one hand, an investment and interest on my part, but also a need to be responsive to my own limitations, so that I can be as effective as possible as a researcher.

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Appendices

Appendix A. University of Nottingham ethical approval and approval of amendments to the project

Dear Ben

Application Authorised: 22041

Make sure you add @hra.nhs.uk to your 'Never Block Sender's Domain' list (accessed from the Junk menu) in Outlook to prevent responses going into your Junk file.

Please read this email in full as it provides you with guidance on the submission process, along with guidance which should be followed during your study and once your study is complete.

Your application has been e-authorised in IRAS by the sponsor – please do not make any amendments to your authorised IRAS forms (even clicking on a question will invalidate the authorisation – you can add the REC reference (if applicable) but that is all).

Please ensure that you have attached all study related documents to your IRAS checklist otherwise it will not be deemed a valid application.

Proportionate review

If you haven't done so yet, we strongly recommend that you use the Proportionate Review toolkit to consider whether your study might be suitable for Proportionate Review or whether it requires a full REC review before submitting. If this is the case then you will be notified when you book your application in through the Online Booking Service.

Copies of finalised documents

Please if you haven't already send us the version of ALL study documents you are submitting to the HRA – ensuring that all comments are deleted and all tracked changes are accepted. Once you have received full HRA/ethics approval please send me a copy of all Final Version 1.0 documents

Sponsor letter and Certificate of Insurance

Please find attached your sponsor letter and certificate of insurance which is required for your HRA Approval submission. **Please upload these to your checklist.**

How to book your application for HRA Approval

- You will need to book your application online using the 'E-submissions' tab in IRAS. You will need to provide the IRAS Project ID and key information about your project.

Training and guidance will be available via the IRAS website. You can also watch a short video to see how to use the online booking service.

- When you are ready to book, click the ‘book application’ button. This will take you through to the electronic booking module. The booking module uses a separate login. If you have not used the booking module before, you will need to create a new account by clicking ‘create account’.
- If you require assistance during the online booking process you can call 0207 104 8000.
- Confirmation of your booking will be provided via email - please forward a copy of this to the sponsor (if we have not already been copied in to the email sent)

***IMPORTANT: Booking and submission must be completed on the same day ***

- As soon as you have your booking confirmation you need to electronically submit your application
- Firstly add your ethics committee booking information to page 1 of the IRAS form the click “E-submit application” (on the submission tab in IRAS)
  This will electronically submit your form and supporting documents uploaded to the checklist.
  Note: The submission history (on submission tab) provides a record of your submission and updates on its status.
- We suggest Checking these status updates to ensure that your application has been accepted for processing.
- The ‘E-submit application’ button will be disabled when your application has been submitted and/or it is being processed.
- After you have submitted your application

Please contact the HRA, if you have:

  - Made a mistake and/or need to withdraw your application;
  - Need to supply additional supporting documents;
  - Need to submit a response to a request from HRA. Refer to HRA Website for guidance.

Agreements:

You will be using the PIC agreement for your sites identified as PICs. This agreement has been sent to you previously. This will need to be included on the IRAS checklist and circulated as part of the site R&D submission (see later section).

Sponsor/CI agreement

I've attached the Sponsor/CI agreement for the study. Please can you arrange for the CI to sign the attached agreement and then email it back to us atsponsor@nottingham.ac.uk

This can be a scanned signature or the CI can type their name on the agreement to confirm agreement to terms and conditions. We will then send you a copy back with the sponsor signature for your study folder. **This does not need to be included on the IRAS checklist.**

Final Version of Study Documents:

As sponsor we **must** keep a copy of the documents submitted to the ethics committee, if you haven't already, please send me the **final clean version** of your documents. You also need to send me a copy of the fully authorised and submitted IRAS form (these may be found in 'Submission History' which is under the 'e-submission' tab of your IRAS form and 'Submission History').

HRA Initial Assessment/Ethics changes (provisional opinion):

Please note that if the HRA initial assessment or HRA ethics committee requests any changes to any documents these should also be sent to sponsor@nottingham.ac.uk as we must keep a record of the final ethics committee approved version of your study documents you will also need to update your 'local document package' accordingly.

Amendments (after HRA Approval): See Sponsor SOP TA013 Amendments

Should there be any subsequent amendment to any of the study documents please refer to SOP TA013 Protocol Amendments, available on the RGS webpage. Copies of amendments including the amendment tool (found in IRAS) should be submitted to sponsor@nottingham.ac.uk for sponsor review and sign off/form locking prior to submission to the HRA and HRA ethics.

R&D submission:

I have also provided guidance in relation to the R&D approval process in more detail below:

Once you have received confirmation that your ethics application is valid, you can now apply for R&D approval as well. It is best to try to submit to the HRA and R&D at the same time to help speed up the process.

For your R&D application you will need collate your 'local information pack'

This should comprise of the same documents that have been added to the IRAS form checklist in IRAS. Once you have received any correspondence from the HRA (for HRA approval) this should also be added to your local document package.

You will then need to email your 'local information pack' to the relevant R&D department for them to begin their review (this can be done simultaneously with your ethics application to save time). Please use the HRA email template attached. You may need to forward any additional correspondence from HRA/HRA ethics once this is received

Please copy me in

Progress Reports:

It is a condition of your ethical approval that a progress report is submitted to ethics yearly on the anniversary of your ethics approval date (not first participant recruited). Failure to do this, may result in a suspension of your favourable opinion by the ethics committee. Please ensure that you complete your progress report and also send a copy to the sponsor representative (me) and any R&D departments.

End of Study Declaration:

Once your study is complete you MUST notify the sponsor, ethics committee, NOMS (if appropriate) and all R&D departments involved with your study.

To do this you MUST complete a copy of the end of study declaration (within 90 days of the data collection period completing (including any follow-up)) and submit a final report (within 12 months of notifying that the study is complete). If you have any queries regarding this please do not hesitate to contact me.

The form may be accessed here:

http://www.hra.nhs.uk/resources/during-and-after-your-study/end-of-study-notification-studies-other-than-clinical-trials-of-investigational-medicinal-products/

You can also use this form for notifying UoN ethics committees

See also Sponsor SOP QA005 Archiving – for archiving of your study documents

All **Sponsor SOPs, Record Forms and Work Instructions** may be found here:

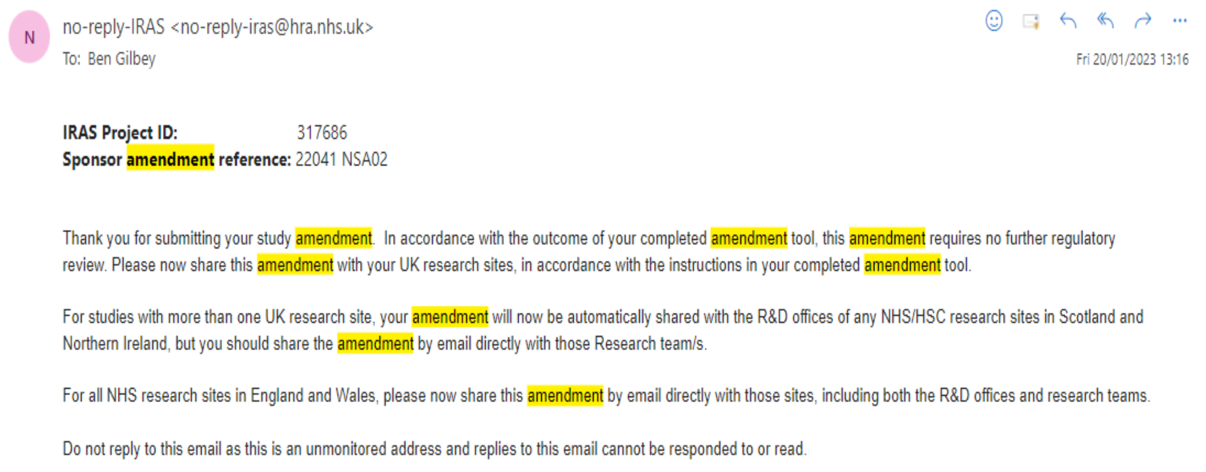
https://workspace.nottingham.ac.uk/display/ResG/SOPs%2C+Record+Forms+and+Work+Instructions

Please note that this is only accessible to University of Nottingham staff, if you are student, your academic supervisor will need to access these documents for you

Please ensure that you submit your application to the HRA within 2 working days, you must also submit to any R&D departments at the SAME time. Please do not delay submitting your applications.

Any queries please do not hesitate to contact me.

Sarah Flynn
Research Governance Co-ordinator



no-reply-IRAS <no-reply-iras@hra.nhs.uk>
To: Ben Gilbey

Fri 20/01/2023 13:16

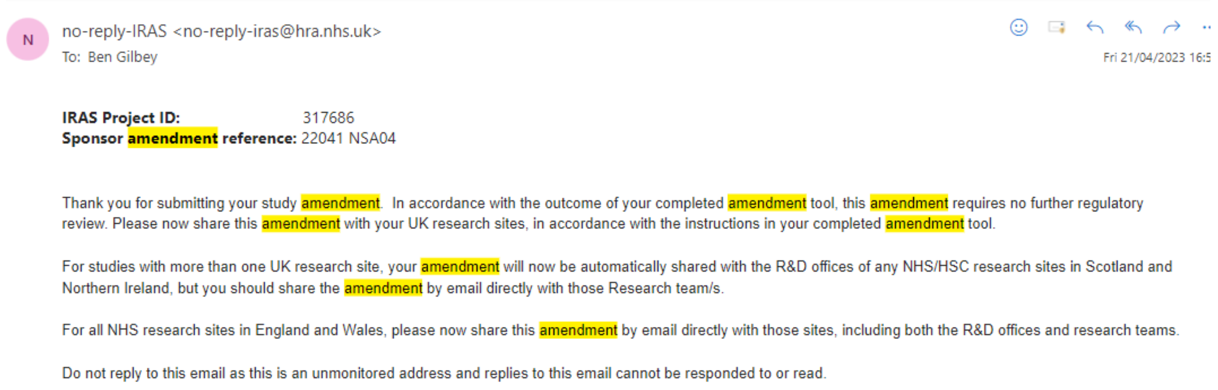
IRAS Project ID: 317686
Sponsor amendment reference: 22041 NSA02

Thank you for submitting your study amendment. In accordance with the outcome of your completed amendment tool, this amendment requires no further regulatory review. Please now share this amendment with your UK research sites, in accordance with the instructions in your completed amendment tool.

For studies with more than one UK research site, your amendment will now be automatically shared with the R&D offices of any NHS/HSC research sites in Scotland and Northern Ireland, but you should share the amendment by email directly with those Research team/s.

For all NHS research sites in England and Wales, please now share this amendment by email directly with those sites, including both the R&D offices and research teams.

Do not reply to this email as this is an unmonitored address and replies to this email cannot be responded to or read.



no-reply-IRAS <no-reply-iras@hra.nhs.uk>
To: Ben Gilbey

Fri 21/04/2023 16:5

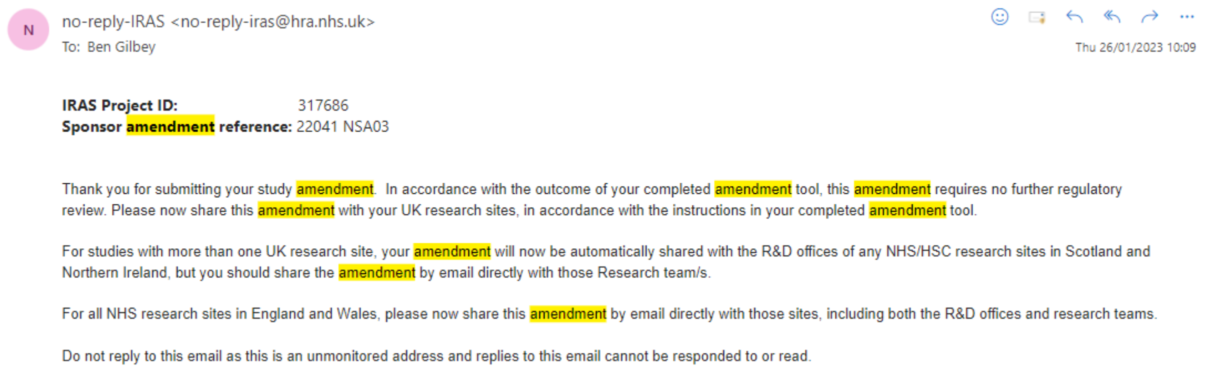
IRAS Project ID: 317686
Sponsor amendment reference: 22041 NSA04

Thank you for submitting your study amendment. In accordance with the outcome of your completed amendment tool, this amendment requires no further regulatory review. Please now share this amendment with your UK research sites, in accordance with the instructions in your completed amendment tool.

For studies with more than one UK research site, your amendment will now be automatically shared with the R&D offices of any NHS/HSC research sites in Scotland and Northern Ireland, but you should share the amendment by email directly with those Research team/s.

For all NHS research sites in England and Wales, please now share this amendment by email directly with those sites, including both the R&D offices and research teams.

Do not reply to this email as this is an unmonitored address and replies to this email cannot be responded to or read.



no-reply-IRAS <no-reply-iras@hra.nhs.uk>
To: Ben Gilbey

Thu 26/01/2023 10:09

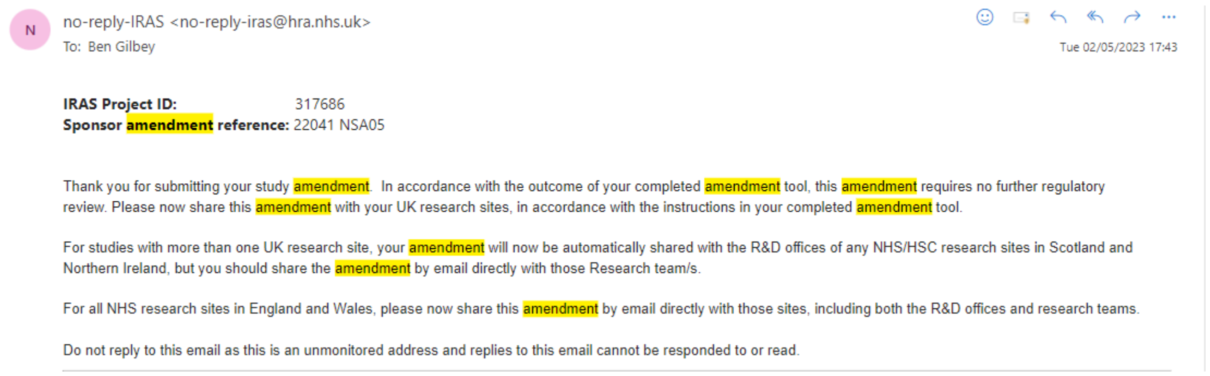
IRAS Project ID: 317686
Sponsor amendment reference: 22041 NSA03

Thank you for submitting your study amendment. In accordance with the outcome of your completed amendment tool, this amendment requires no further regulatory review. Please now share this amendment with your UK research sites, in accordance with the instructions in your completed amendment tool.

For studies with more than one UK research site, your amendment will now be automatically shared with the R&D offices of any NHS/HSC research sites in Scotland and Northern Ireland, but you should share the amendment by email directly with those Research team/s.

For all NHS research sites in England and Wales, please now share this amendment by email directly with those sites, including both the R&D offices and research teams.

Do not reply to this email as this is an unmonitored address and replies to this email cannot be responded to or read.



no-reply-IRAS <no-reply-iras@hra.nhs.uk>
To: Ben Gilbey

Tue 02/05/2023 17:43

IRAS Project ID: 317686
Sponsor amendment reference: 22041 NSA05

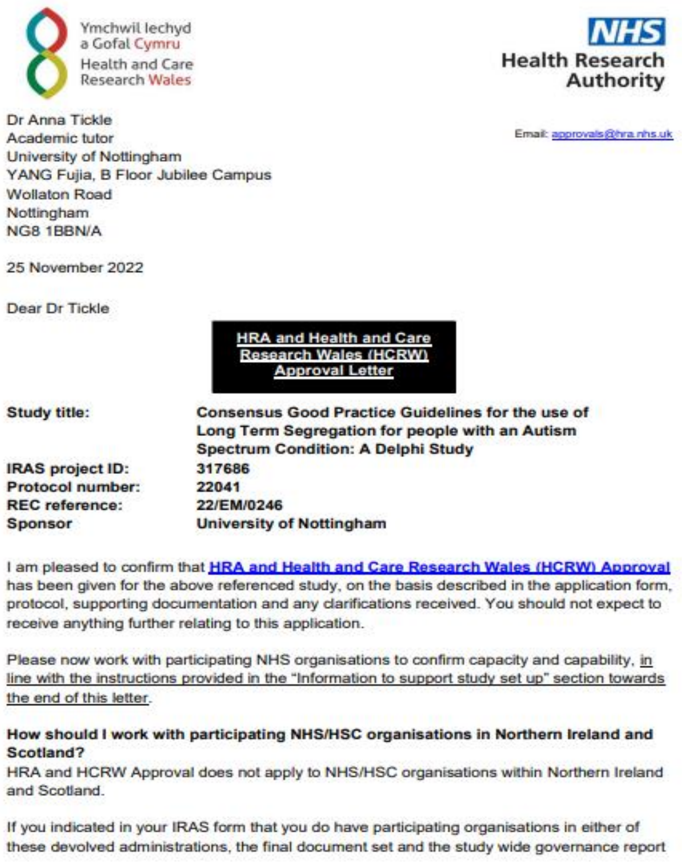
Thank you for submitting your study amendment. In accordance with the outcome of your completed amendment tool, this amendment requires no further regulatory review. Please now share this amendment with your UK research sites, in accordance with the instructions in your completed amendment tool.

For studies with more than one UK research site, your amendment will now be automatically shared with the R&D offices of any NHS/HSC research sites in Scotland and Northern Ireland, but you should share the amendment by email directly with those Research team/s.

For all NHS research sites in England and Wales, please now share this amendment by email directly with those sites, including both the R&D offices and research teams.

Do not reply to this email as this is an unmonitored address and replies to this email cannot be responded to or read.

Appendix B. IRAS ethical approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Email: approvals@hra.nhs.uk

Dr Anna Tickle
Academic tutor
University of Nottingham
YANG Fujia, B Floor Jubilee Campus
Wollaton Road
Nottingham
NG8 1BBN/A

25 November 2022

Dear Dr Tickle

HRA and Health and Care Research Wales (HCRW) Approval Letter

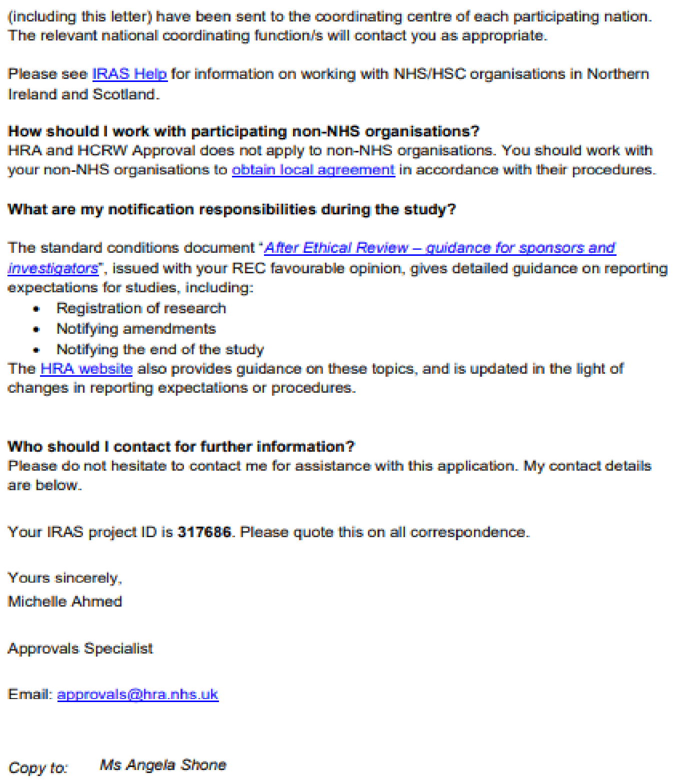
Study title:	**Consensus Good Practice Guidelines for the use of Long Term Segregation for people with an Autism Spectrum Condition: A Delphi Study**
IRAS project ID:	**317686**
Protocol number:	**22041**
REC reference:	**22/EM/0246**
Sponsor	**University of Nottingham**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report



(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **317686**. Please quote this on all correspondence.

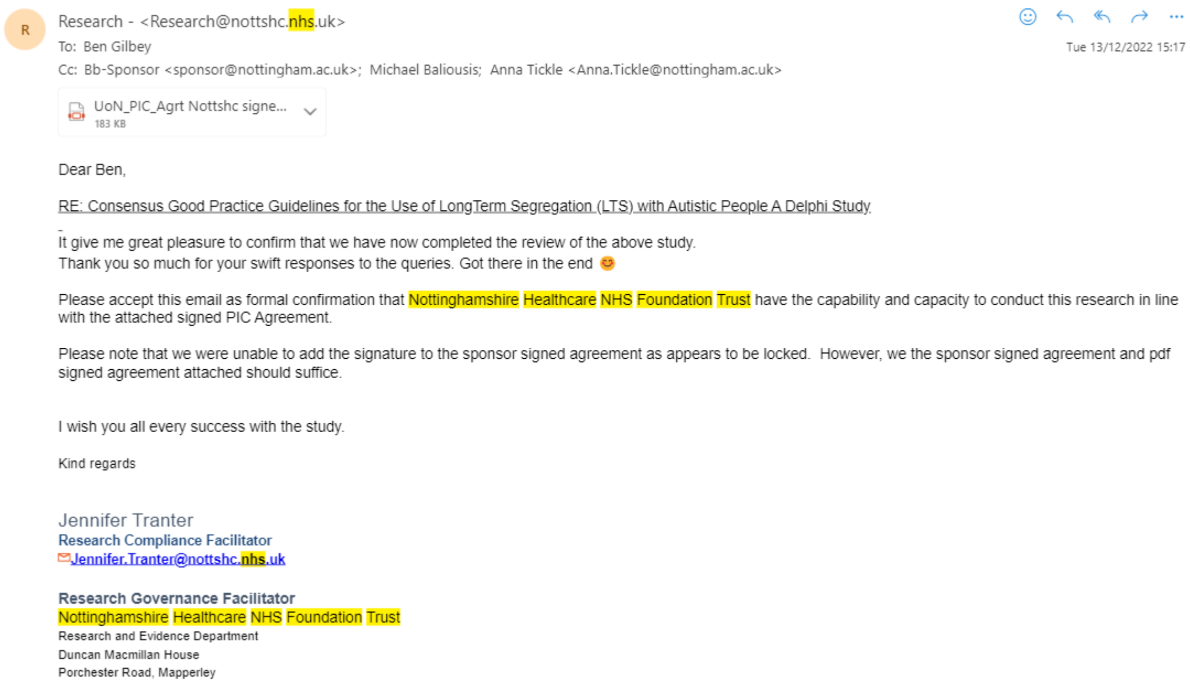
Yours sincerely,
Michelle Ahmed

Approvals Specialist

Email: approvals@hra.nhs.uk

Copy to: *Ms Angela Shone*

Appendix C. Nottinghamshire Healthcare NHS Foundation Trust ethical approval



Research - <Research@nottshc.nhs.uk>
To: Ben Gilbey
Cc: Bb-Sponsor <sponsor@nottingham.ac.uk>; Michael Baliousis; Anna Tickle <Anna.Tickle@nottingham.ac.uk>

Tue 13/12/2022 15:17

UoN_PIC_Agrt Nottshc signe...
183 KB

Dear Ben,

RE: Consensus Good Practice Guidelines for the Use of LongTerm Segregation (LTS) with Autistic People A Delphi Study

It give me great pleasure to confirm that we have now completed the review of the above study.
Thank you so much for your swift responses to the queries. Got there in the end 😊

Please accept this email as formal confirmation that Nottinghamshire Healthcare NHS Foundation Trust have the capability and capacity to conduct this research in line with the attached signed PIC Agreement.

Please note that we were unable to add the signature to the sponsor signed agreement as appears to be locked. However, we the sponsor signed agreement and pdf signed agreement attached should suffice.

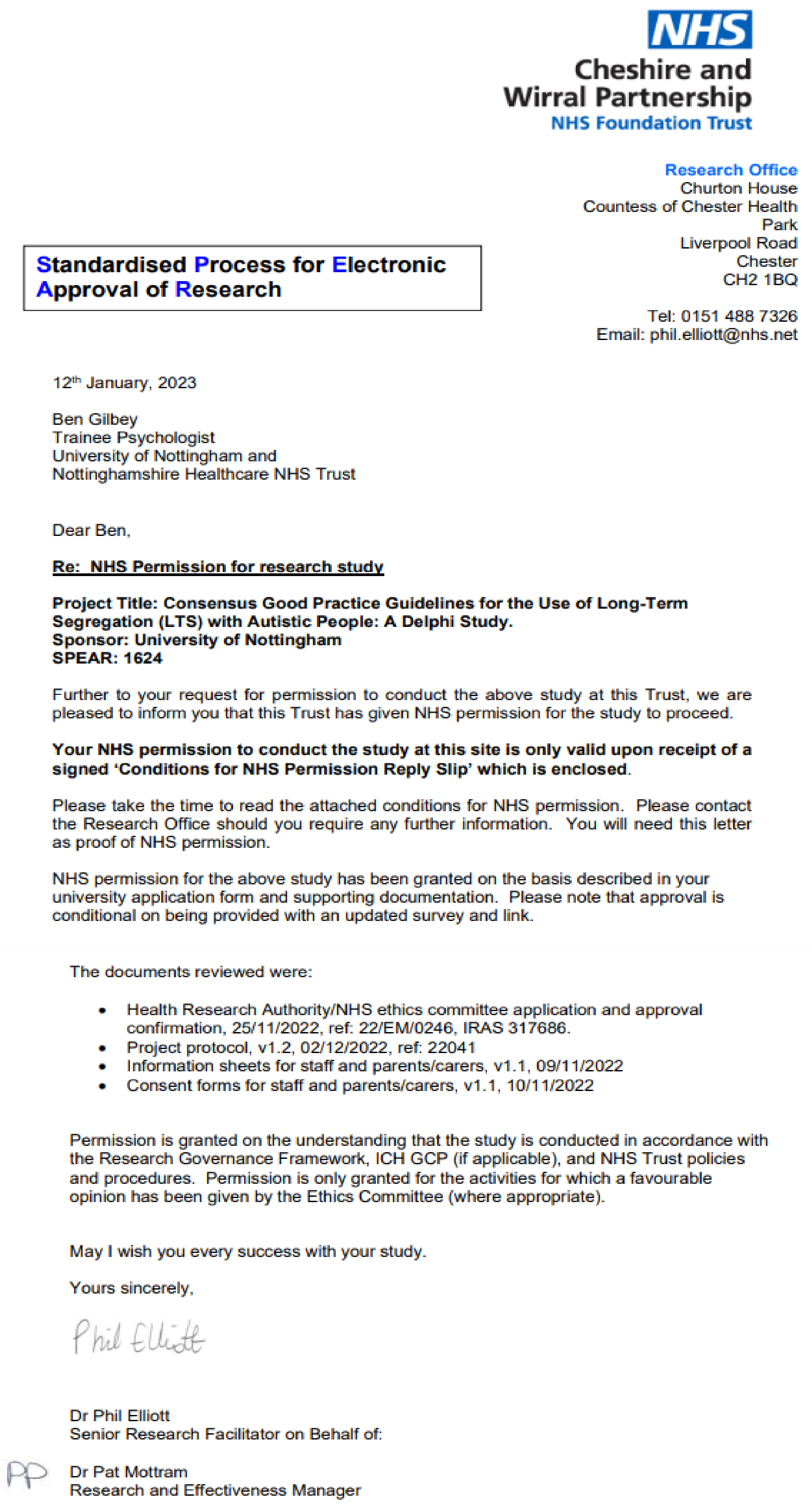
I wish you all every success with the study.

Kind regards

Jennifer Tranter
Research Compliance Facilitator
Jennifer.Tranter@nottshc.nhs.uk

Research Governance Facilitator
Nottinghamshire Healthcare NHS Foundation Trust
Research and Evidence Department
Duncan Macmillan House
Porchester Road, Mapperley

Appendix D. Cheshire and Wirral NHS ethical approval



NHS
Cheshire and
Wirral Partnership
NHS Foundation Trust

Research Office
Churton House
Countess of Chester Health
Park
Liverpool Road
Chester
CH2 1BQ

Tel: 0151 488 7326
Email: phil.elliott@nhs.net

Standardised Process for Electronic Approval of Research

12th January, 2023

Ben Gilbey
Trainee Psychologist
University of Nottingham and
Nottinghamshire Healthcare NHS Trust

Dear Ben,

Re: NHS Permission for research study

Project Title: Consensus Good Practice Guidelines for the Use of Long-Term Segregation (LTS) with Autistic People: A Delphi Study.
Sponsor: University of Nottingham
SPEAR: 1624

Further to your request for permission to conduct the above study at this Trust, we are pleased to inform you that this Trust has given NHS permission for the study to proceed.

Your NHS permission to conduct the study at this site is only valid upon receipt of a signed 'Conditions for NHS Permission Reply Slip' which is enclosed.

Please take the time to read the attached conditions for NHS permission. Please contact the Research Office should you require any further information. You will need this letter as proof of NHS permission.

NHS permission for the above study has been granted on the basis described in your university application form and supporting documentation. Please note that approval is conditional on being provided with an updated survey and link.

The documents reviewed were:

- Health Research Authority/NHS ethics committee application and approval confirmation, 25/11/2022, ref: 22/EM/0246, IRAS 317686.
- Project protocol, v1.2, 02/12/2022, ref: 22041
- Information sheets for staff and parents/carers, v1.1, 09/11/2022
- Consent forms for staff and parents/carers, v1.1, 10/11/2022

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework, ICH GCP (if applicable), and NHS Trust policies and procedures. Permission is only granted for the activities for which a favourable opinion has been given by the Ethics Committee (where appropriate).

May I wish you every success with your study.

Yours sincerely,

Phil Elliott

Dr Phil Elliott
Senior Research Facilitator on Behalf of:

PP Dr Pat Mottram
Research and Effectiveness Manager

Appendix E. MDT staff participant information sheet

University of Nottingham
UK | CHINA | MALAYSIA

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

Participant Information Sheet (Staff)
(Final version 1.1: 09.11.22)

IRAS Project ID: 317686

Title of Study: **Consensus Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People: A Delphi Study**
Name of Chief Investigator: Dr Anna Tickle
Local Researcher(s): N/A
Student/investigator: Ben Gilbey

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

The study aims to consult with experts who have experience of the use of long-term segregation (LTS) with autistic people with learning disabilities, and carers/parents who have autistic family members who have a learning disability and have experienced LTS, to then produce potential good practice recommendations in the use of LTS with autistic people with learning disabilities in assessment and treatment units (ATUs). This will be done through interviewing members of multidisciplinary teams (MDT) and carers/parents for their views on good practice in the use of LTS with autistic people with learning disabilities. At the end of the interview, participants will be asked to provide recommendations to guide practice in the use of LTS with autistic people with learning disabilities. After the interviews participants will then participate in a series of survey rounds where they will be asked to vote anonymously on the recommendations to guide practice that were made during the interviews. The aim will be to achieve consensus on recommendations to guide practice using a method of consensus building (the Delphi method), which may then be published to inform good practice in the use of LTS with autistic people.

What will happen to the results of the research study?

The results will then be written up as part of my Doctorate in Clinical Psychology at the University of Nottingham. I will also write a shorter version to be published in a research journal. The published research paper will not reveal any of your personal information, with names being anonymised and personal information which could identify you will not be included. A copy of the results, including final recommendations (if consensus is achieved) will be sent to all participants.

It is possible that interview data may also be subject to secondary analysis to examine key themes relating to good practice in the use of LTS with autistic people with learning disabilities. This would be done by members of the team and another trainee clinical psychologist, bound by the same guidelines and policies as the current project. All data would remain anonymous.

Who can take part?

The study is seeking to recruit participants across the range of professional roles within NHS MDTs that may have experience of working with autistic people who are in LTS, as well as carers and parents of autistic people who either have been or are currently in LTS. To participant you must:

- Be over 18 years of age
- Have sufficient understanding of spoken and written English
- Have access to a device such as a computer or laptop that is connected to the internet
- Have a minimum of 1 year's clinical experience in a role that includes working with autistic people with learning disabilities in LTS in ATUs

- If you have retired, this must have been within the last year from a clinical role in which you worked with autistic people with learning disabilities who were in LTS in ATUs.

Specific criteria related to members of the multidisciplinary team (MDT)

MDT. These will be identified as responsible clinicians, clinical psychologists, speech and language therapists, physiotherapists, occupational therapists, ward managers, nurses, clinical nurse specialists, healthcare assistants, and advocates who have experience of caring for autistic people with learning disabilities who have been or who are currently in LTS. The study will aim to recruit two of each from each professional role.

Why have I been invited?

You have been invited to participate because you are a member of an MDT who has experience of the use of LTS with autistic people with learning disabilities in ATUs. We are aiming to invite two people from each of the MDT roles listed above and two carers/parents to offer their expertise and lived experience. Not everyone who expresses an interest to participate may be able to participate, as participation will depend on meeting the inclusion criteria and if the study has finished recruiting or not.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, you will have an opportunity to discuss the study with the investigator (Ben Gilbey) prior to providing consent to participate. You will then be given this information sheet to keep and be asked to sign an online consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?

The study will last approximately one year and will consist of the following:

You will be invited to participate in an online, videorecorded interview with the student/investigator (Ben Gilbey) that will last approximately 1 hour. Interviews will be recorded via Microsoft Teams (MST). Interview recordings will be kept on password-protected laptop and identifiable data will be pseudonymised. This will be achieved by assigning you a four-digit number. The interview will be arranged for a time that is convenient for you between December 2022 and February 2023 and will take place online.

You will then be asked to take part in up to four separate surveys which you will receive via email and asked to complete within two weeks of receiving them. The first survey will be sent around February 2023, with the second survey being sent in March 2023, the third being sent in April 2023, and the fourth being sent in May 2023. Typically, only two-three surveys are required, but there may be up to four. Each survey will require approximately 30 minutes of your time. You will have two weeks from when you receive the survey to complete it and return it. If you have not completed the survey by the end of the first week, you will be sent an email prompting you to do so. If you have not completed the survey at the end of the second week, the researcher (Ben Gilbey) will send a second email, informing you of the progress of the round, and to ask if you are able to find the time to complete the return the survey. Your continued participation in the study will require completion and return of the current survey round. If you do not complete and return the current survey before the next round begins, you will be removed from the study.

If consensus is achieved, a final round will be used to share the proposed recommendations and obtain feedback from participants on the recommendations, but further changes will not be made. The final recommendations will be accompanied by clinical vignettes (examples to illustrate each recommendation) to support application of the recommendations in practice. These will be taken from the examples of clinical practice you provide during the interview, with the final vignettes being developed by the student/investigator. The clinical vignettes will depict clinical scenarios related to each recommendation, to help clinicians apply the recommendations in clinical practice. **All clinical vignettes will be anonymous**, and the finalised recommendations with clinical vignettes will be shared with you to check if clinical vignettes identify you or anyone you have worked with, to ensure confidentiality and anonymity.

You will not need to meet the student/investigator once you have completed your interview.

The interview data will also be retained for analysis in the event that consensus is not achieved. Analysis of interview data would take place in the event that consensus was not achieved, in order to explore the key themes related to the use of LTS with autistic people.

What will I be asked in the interview?

During the interview, you will be asked to share your experiences relating to having worked clinically with autistic people with learning disabilities who have been in LTS. You will be asked to describe examples of when the use of LTS has gone well and why you think this was, when it has not gone well and why you think this was, as well as being asked to share recommendations for good practice in using LTS with autistic people.

Sharing detailed examples will be an important part of the interview, but **you will be asked not to name specific individuals (e.g. names of family members, the person you care for and/or staff members) or names and locations of services when being interviewed.** This is to ensure that anonymity and confidentiality are maintained throughout the interview process.

However, if during the interview a current concern is raised that may require a safeguarding response, the interviewer (Ben Gilbey) will raise this with you at the end of the interview and will bring it to the attention of the research team. You may then be contacted by the team to discuss how best to address the concern raised.

Expenses and payments

Participants will not be paid to participate in the study, but those who complete participation in the research (i.e. completing interviews and survey rounds) will have the option of receiving a £10 Amazon voucher or an equivalent donation to the National Autistic Society, or an alternative autism charity of their choice.

What are the possible disadvantages and risks of taking part?

In participating in this research, you will be required to give up between 120-180 minutes of your time, depending on the number of survey rounds. You will be asked about difficulties and challenges in the use of LTS with autistic people, which may at time be difficult to talk about.

We understand the sensitive nature of talking about this subject matter. It will be possible for you to take breaks during the interview, and you are free to withdraw from the research at any time.

If you feel distressed by your participation in the study but do not want to talk to the research team about it, you can contact one of the numbers provided at the bottom of this document.

What are the possible benefits of taking part?

We cannot promise the study will help you but the information we get from this study may help to inform good practice on the use of LTS with autistic people. The recommendations produced may help staff working with autistic people in LTS to ensure that their needs are being met and that their human rights are being protected.

What if there is a problem?

If you have any concerns about any part of the study, you can speak to the researchers who will do their best to answer your questions and address your concerns. The contact details for the researchers are given at the end of this sheet. If you are still unhappy and would like to complain formally, you can do this by FMHS ethics committee- ResearchEthics@nottingham.ac.uk, or by contacting The Patient Advice and Liaison Service (Tel: 0115 993 4542; Email:PALSandComplaints@nottshc.nhs.uk).

In the event that something does go wrong, and you are harmed during the research, and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?

The responses of all participants will be made known to all other participants and will be documented on the copies of the surveys received, **but all responses will be anonymised**. The names of those contributing will remain confidential both during and after the study.

Participants may be involved in high profile cases either locally or nationally. Participants will be asked to keep the details of cases anonymous and will not be asked to give any specific identifiable information.

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, we will use information collected from you during the course of the research. This information will be kept strictly confidential, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for three months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, reuse (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. With regards to practitioner involvement, if anything is disclosed that is considered a breach of professional recommendations, then it may be necessary for action to be taken in this instance.

What will happen if I don’t want to carry on with the study?
Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to alter study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

Who is organising the research?
The research is organised by the University of Nottingham.

Who has reviewed the study?
The research has been reviewed by a Research Ethics Committee to protect your interests and welfare. This study has been reviewed and granted a favourable opinion by the East Midlands-Derby Research Ethics Committee, who confirmed that it is useful and safe for you to take part.

What if I have more questions?
If you have more questions, please feel free to contact me and/or other members of the research team. Our contact details are on the bottom of this sheet. We will be happy to talk with you.

How will we use information about you?
We will need to use information from you for this research project.
This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.
People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.
We will keep all information about you safe and secure.
Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?
You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to ben.gilbey@nottingham.ac.uk, or
- by ringing us on +44 (0) 115 846 6646.

Thanks for your time,
Ben

Further information and contact details
Lead researcher: Ben Gilbey
Benjamin.gilbey@nottshc.nhs.uk
Supervised by:
Dr Anna Tickle (Chief investigator): anna.tickle1@nottingham.ac.uk
Tel: +44 (0) 115 846 6646
Dr Michael Baliousis (Co-investigator): mbaliousis@lincoln.ac.uk
Tel: +44 (0)1522 837733.
Postal address:
Ben Gilbey
Yang Fujia Building, Division of Psychiatry and Applied Psychology,
School of Medicine, University of Nottingham,
Jubilee Campus, Wollaton Road,
Nottingham,
NG8 1BB

Helplines
Samaritans Nottingham, Tel: 116 123 (free), Tel: 0330 094 5717 (charges apply), Website: www.samaritans.org
NHS
NHS Emergency, 999
NHS Non-emergency, 111

Appendix F. Parents and carers participant information sheet

Participant Information Sheet (Parents/Carers)
(Final version 1.1: 09.11.22)

IRAS Project ID: 317686

Title of Study: **Consensus Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People: A Delphi Study**
Name of Chief Investigator: Dr Anna Tickle
Local Researcher(s): N/A
Student/investigator: Ben Gilbey

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

The study aims to consult with experts who have experience of the use of long-term segregation (LTS) with autistic people with learning disabilities, and carers/parents who have autistic family members with learning disabilities who have experienced LTS, to then produce potential good practice guidelines in the use of LTS with autistic people with learning disabilities in assessment and treatment units (ATUs). This will be done through interviewing members of multidisciplinary teams (MDT) and carers/parents for their views on good practice in the use of LTS with autistic people. At the end of the interview, participants will be asked to provide recommendations to guide practice in the use of LTS with autistic people with learning disabilities. After the interviews participants will then participate in a series of survey rounds where they will be asked to vote anonymously on the recommendations to guide practice that were made during the interviews. The aim will be to achieve consensus on good practice recommendations using a method of consensus building (the Delphi method), which may then be published to inform good practice in the use of LTS with autistic people.

What will happen to the results of the research study?

The results will then be written up as part of my Doctorate in Clinical Psychology at the University of Nottingham. I will also write a shorter version to be published in a research journal. The published research paper will not reveal any of your personal information, with names being anonymised and personal information which could identify you will not be included. A copy of the results, including final recommendations (if consensus is achieved) will be sent to all participants.

It is possible that interview data may also be subject to secondary analysis to examine key themes relating to good practice in the use of LTS with autistic people with learning disabilities. This would be done by members of the team and another trainee clinical psychologist, bound by the same guidelines and policies as the current project. All data would remain anonymous.

Who can take part?
The study is seeking to recruit participants across the range of professional roles within NHS MDTs that may have experience of working with autistic people who are in LTS, and carers and parents of autistic people who either have been or are currently in LTS. To participant you must:

- Be over 18 years of age
- Have sufficient understanding of spoken and written English
- Have access to a device such as a computer or laptop that is connected to the internet

Specific criteria related to carers/parents are outlined below.

Carers/parents. These will be identified as any carer or parent who cares for an autistic person with a learning disability (who may be a family member) who has been in or is currently in LTS in an ATU. The study aims to recruit two parents/carers.

Why have I been invited?
You have been invited to participate because you are a carer or parent who cares for an autistic person with a learning disability (who may be a family member) who has been in or is currently in LTS in an ATU. We are aiming to invite two carers/parents to offer their expertise and lived experience. Not everyone who expresses an interest to participate may be able to participate, as participation will depend on meeting the inclusion criteria and if the study has finished recruiting or not.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part, you will have an opportunity to discuss the study with the investigator (Ben Gilbey) prior to providing consent to participate. You will then be given this information sheet to keep and be asked to sign an online consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

What will happen to me if I take part?
The study will last approximately one year and will consist of the following:

You will be invited to participate in an online, videorecorded interview with the student/investigator (Ben Gilbey) that will last approximately 1 hour. Interviews will be recorded via Microsoft Teams (MST). Interview recordings will be kept on password-protected laptop and identifiable data will be pseudonymised. This will be achieved by assigning you a four-digit number. The interview will be arranged for a time that is convenient for you between December 2022 and January 2023 and will take place online.

You will then be asked to take part in up to four separate surveys which you will receive via email and asked to complete within two weeks of receiving them. The first survey will be sent around February 2023, with the second survey being sent in March 2023, the third being sent in April 2023, and the fourth being sent in May 2023. Typically, only two-three surveys are required, but there may be up to four. Each survey will require approximately 30 minutes of your time. You will have two weeks from when you receive the survey to complete it and return it. If you have not completed the survey by the end of the first week, you will be sent an email prompting you to do so. If you have not completed the survey at the end of the second week, the researcher (Ben Gilbey) will send a second email, informing you of the progress of the round, and to ask if you are able to find the time to complete the return the survey. Your continued participation in the study will require completion and return of the current survey round. If you do not complete and return the current survey before the next round begins, you will be removed from the study.

If consensus is achieved, a final round will be used to share the proposed recommendations and obtain feedback from participants on the recommendations, but further changes will not be made. The final recommendations will be accompanied by clinical vignettes (examples to illustrate each recomendation) to support application of the recommendations in practice. These will be taken from the examples of clinical practice you provide during the interview, with the final vignettes being developed by the student/investigator. The clinical vignettes will depict clinical scenarios related to each recommendation, to help clinicians apply the recommendations in clinical practice. **All clinical vignettes will be anonymous**, and the finalised recommendations with clinical vignettes will be shared with you to check if clinical vignettes identify you or anyone you have worked with, to ensure confidentiality and anonymity.

You will not need to meet the student/investigator once you have completed your interview.

The interview data will also be retained for analysis in the event that consensus is not achieved. Analysis of interview data would take place in the event that consensus was not achieved, in order to explore the key themes related to the use of LTS with autistic people.

What will I be asked in the interview?

During the interview, you will be asked to share your experiences relating to having an autistic family member and/or caring for an autistic person who has been in LTS. You will be asked to describe examples of when the use of LTS has gone well and why you think this was, when it has not gone well and why you think this was, as well as being asked to share recommendations for good practice in using LTS with autistic people.

Sharing detailed examples will be an important part of the interview, but **you will be asked not to name specific individuals (e.g. names of family members, the person you care for and/or staff members) or names and locations of services when being interviewed.** This is to ensure that anonymity and confidentiality are maintained throughout the interview process.

However, if during the interview a current concern is raised that may require a safeguarding response, the interviewer (Ben Gilbey) will raise this with you at the end of the interview and will bring it to the attention of the research team. You may then be contacted by the team to discuss how best to address the concern raised.

Expenses and payments

Participants will not be paid to participate in the study, but those who complete participation in the research (i.e. completing interviews and survey rounds) will have the option of receiving a £10 Amazon voucher or an equivalent donation to the National Autistic Society, or an alternative autism charity of their choice.

What are the possible disadvantages and risks of taking part?
In participating in this research, you will be required to give up between 120-180 minutes of your time, depending on the number of survey rounds. You will be asked about difficulties and challenges in the use of LTS with autistic people, which may at time be difficult to talk about.

We understand the sensitive nature of talking about this subject matter. It will be possible for you to take breaks during the interview, and you are free to withdraw from the research at any time.

If you feel distressed by your participation in the study but do not want to talk to the research team about it, you can contact one of the numbers provided at the bottom of this document.

What are the possible benefits of taking part?
We cannot promise the study will help you but the information we get from this study may help to inform good practice on the use of LTS with autistic people. The recommendations produced may help staff working with autistic people in LTS to ensure that their needs are being met and that their human rights are being protected.

What if there is a problem?
If you have any concerns about any part of the study, you can speak to the researchers who will do their best to answer your questions and address your concerns. The contact details for the researchers are given at the end of this sheet. If you are still unhappy and would like to complain formally, you can do this by FMHS ethics committee-ResearchEthics@nottingham.ac.uk, or by contacting The Patient Advice and Liaison Service (Tel: 0115 993 4542; Email:PALSandComplaints@nottshc.nhs.uk).

In the event that something does go wrong, and you are harmed during the research, and this is due to someone's negligence then you may have grounds for a legal action for compensation against the University of Nottingham but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

Will my taking part in the study be kept confidential?
The responses of all participants will be made known to all other participants and will be documented on the copies of the surveys received, **but all responses will be anonymised**. The names of those contributing will remain confidential both during and after the study.

Participants may be involved in high profile cases either locally or nationally. Participants will be asked to keep the details of cases anonymous and will not be asked to give any specific identifiable information.

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, we will use information collected from you during the course of the research. This information will be kept strictly confidential, stored in a secure and locked office, and on a password protected database at the University of Nottingham. Under UK Data Protection laws the University is the Data Controller (legally responsible for the data security) and the Chief Investigator of this study (named above) is the Data Custodian (manages access to the data). This means we are responsible for looking after your information and using it properly. Your rights to access, change or move your information are limited as we need to manage your information in specific ways to comply with certain laws and for the research to be reliable and accurate. To safeguard your rights we will use the minimum personally – identifiable information possible.

You can find out more about how we use your information and to read our privacy notice at: https://www.nottingham.ac.uk/utilities/privacy.aspx.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

Your contact information will be kept by the University of Nottingham for three months after the end of the study so that we are able to contact you about the findings of the study and possible follow-up studies (unless you advise us that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (research data) will be kept securely for 7 years. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team given permission by the data custodian will have access to your personal data.

In accordance with the University of Nottingham's, the Government's and our funders' policies we may share our research data with researchers in other Universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, reuse (and therefore avoiding duplication of research) and to understand the bigger picture in particular areas of research. Data sharing in this way is usually anonymised (so that you could not be identified) but if we need to share identifiable information, we will seek your consent for this and ensure it is secure. You will be made aware then if the data is to be shared with countries whose data protection laws differ to those of the UK and how we will protect your confidentiality.

Although what you say to us is confidential, should you disclose anything to us which we feel puts you or anyone else at any risk, we may feel it necessary to report this to the appropriate persons. With regards to practitioner involvement, if anything is disclosed that is considered a breach of professional guidelines, then it may be necessary for action to be taken in this instance.

What will happen if I don't want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw, we will no longer collect any information about you or from you but we will keep the information about you that we have already obtained as we are not allowed to alter study records and this information may have already been used in some analyses and may still be used in the final study analyses. To safeguard your rights, we will use the minimum personally identifiable information possible.

Who is organising the research?

The research is organised by the University of Nottingham.

Who has reviewed the study?

The research has been reviewed by a Research Ethics Committee to protect your interests and welfare. This study has been reviewed and granted a favourable opinion by the East Midlands-Derby Research Ethics Committee, who confirmed that it is useful and safe for you to take part.

What if I have more questions?

If you have more questions, please feel free to contact me and/or other members of the research team. Our contact details are on the bottom of this sheet. We will be happy to talk with you.

How will we use information about you?

We will need to use information from you for this research project.

This information will include your name and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to ben.gilbey@nottingham.ac.uk, or
- by ringing us on +44 (0) 115 846 6646.

Thanks for your time,
Ben

Further information and contact details

Lead researcher: Ben Gilbey
Benjamin.gilbey@nottshc.nhs.uk
Supervised by:
Dr Anna Tickle (Chief investigator): anna.tickle1@nottingham.ac.uk
Tel: +44 (0) 115 846 6646
Dr Michael Baliousis (Co-investigator): mbaliousis@lincoln.ac.uk
Tel: +44 (0)1522 837733.
Postal address:
Ben Gilbey
Yang Fujia Building, Division of Psychiatry and Applied Psychology,
School of Medicine, University of Nottingham,
Jubilee Campus, Wollaton Road,
Nottingham,
NG8 1BB

Helplines
Samaritans Nottingham, Tel: 116 123 (free), Tel: 0330 094 5717 (charges apply), Website: www.samaritans.org
NHS
NHS Emergency, 999
NHS Non-emergency, 111

Appendix G. MDT staff informed consent form.

CONSENT FORM (MDT Staff)
(Final version 1.1 - date 11.11.2022)

Title of Study: Consensus Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People: A Delphi Study

IRAS Project ID: 317686

Name of Researcher(s): Dr Ben Gilbey

Name of Participant:

Please tick the box*

1. I confirm that I have read and understand the information sheet version number 1.1 dated 09.11.22 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far will not be erased and that this information may still be used in the project analysis. ☐
3. I understand that should I choose not to respond to surveys that I will be sent an email reminding me to complete the survey as well as being provided an update of the progress of the current round. I consent to be contacted by email to be prompted to complete a survey if I have not yet done so. ☐
4. I understand that my participation in the study will end if I do not complete a survey round before the following round is set to begin. ☐
5. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

6. I understand that the interview will be video and audio recorded and that anonymous direct quotes from the interview may be used in the study reports and written up as examples of good practice in communication and sent to other participants as part of surveys associated with the research. ☐

7. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

8. I understand that should I disclose any information which the research team feel puts me or anyone else at risk, or where applicable is considered a breach in law, a risk of harm to others, or a breach of professional codes, then it may be necessary to report this to the appropriate persons. ☐

9. I agree to take part in the above study. ☐

Name of Participant　　Date　　Signature

Name of Person taking consent　　Date　　Signature

2 copies: 1 for participant, 1 for the project notes.

Appendix H. Parents and carers informed consent form.

UNITED KINGDOM · CHINA · MALAYSIA

CONSENT FORM (Parents and Carers)
(Final version 1.1 - date 11.11.2022)

Title of Study: Consensus Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People: A Delphi Study

IRAS Project ID: 317686

Name of Researcher(s): Dr Ben Gilbey

Name of Participant:

Please tick the box*

10. I confirm that I have read and understand the information sheet version number 1.1 dated 09.11.22 for the above study and have had the opportunity to ask questions. ☐

11. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far will not be erased and that this information may still be used in the project analysis. ☐

12. I understand that should I choose not to respond to surveys that I will be sent an email reminding me to complete the survey as well as being provided an update of the progress of the current round. I consent to be contacted by email to be prompted to complete a survey if I have not yet done so. ☐

13. I understand that my participation in the study will end if I do not complete a survey round before the following round is set to begin ☐

14. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to collect, store, analyse and publish ☐

information obtained from my participation in this study. I understand that my personal details will be kept confidential.

15. I understand that the interview will be video and audio recorded and that anonymous direct quotes from the interview may be used in the study reports and written up as examples of good practice in communication and sent to other participants as part of surveys associated with the research. ☐

16. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

17. I understand that should I disclose any information which the research team feel puts me or anyone else at risk, or where applicable is considered a breach in law, a risk of harm to others, or a breach of professional codes, then it may be necessary to report this to the appropriate persons. ☐

18. I agree to take part in the above study. ☐

____________________________ ________________ ______________________
Name of Participant Date Signature

_________________________ ________________ ______________________
Name of Person taking consent Date Signature

2 copies: 1 for participant, 1 for the project notes.

Appendix I. Study advert

Study Advertisement

(Final Version 1.3: 23.01.2023)

Do you have direct experience of working clinically with autistic people with learning disabilities in assessment and treatment units (ATUs) who are in long-term segregation (LTS)?

Are you the parent or carer of an autistic person with learning disabilities who has been in or is currently in LTS?

If so, you are invited to take part in research that aims to support staff members and clinicians in improving how LTS is used with autistic people with learning disabilities in ATUs.

What is the aim of the study?

The aim of our research is to produce a set of good practice guidelines to inform the use of LTS with Autistic people, based on the perspectives of clinical staff who have professional experience using LTS with autistic people and parents/carers who care for someone who has been in or is currently in LTS.

Who can take part?

We are looking to recruit members of multidisciplinary teams (MDTs) who have:

- A minimum of 1 year's clinical experience in a role that includes working with autistic people with learning disabilities in ATUs who are in LTS.
- Experience must cover decisions around starting and ending LTS with autistic people with learning disabilities, as well as decisions around what happens when an autistic person is in LTS.
- Left their role in the last year but who have worked in clinical roles for more than a year in which their role included working with autistic people with learning disabilities in ATUs who were in LTS.

And carers/family members who:

- Either care for or are related to an autistic people with learning disabilities who has been in or is currently in LTS.

What will happen if I choose to take part?

Taking part in the research will involve an audio and video-recorded individual interview, lasting about 1 hour. This will be followed by up to four survey rounds (by email) structuring the development of the guidelines. This procedure will take place over a maximum of five months, requiring up to 180 minutes of your time.

Those who participate in the research will have the option of receiving a £10 Amazon voucher or an equivalent donation to the National Autistic Society, or an alternative autism charity of their choice.

What if I know a colleague or parent/carer might be suitable for the research?

If you know other colleagues, or parents/carers who fit the inclusion criteria and might be interested in participating, please share this advert with them.

I am interested in taking part, what next?

If you would like to take part in the study, or you would like to know more, please contact Ben Gilbey, primary investigator at the details below:

E-mail: Ben.gilbey@nottingham.ac.uk

Tel: [Researcher’s telephone number]

Appendix J. MDT interview schedule

University of Nottingham
UK | CHINA | MALAYSIA

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

Interview Schedule-MDT

Draft Semi-Structured Interview Schedule – MDT

Study title: Consensus Based Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People-A Delphi Study

(Final version 1.1 – 11.11.2022)

Opening statement: Thank you for agreeing to be interviewed today to discuss your clinical experiences of the use of long-term segregation (LTS) with autistic people. We will have up to an hour to discuss some of the key issues, possible benefits for autistic people, and aspects of good practice in this area. At the end you will be asked to provide recommendations to guide good practice in the use of LTS with autistic people with learning disabilities, that may inform future practice. If you would like to take a break at any point during the interview, please let me know and we can facilitate this. If you are finding any of the issues we discuss uncomfortable to talk about please let me know. To confirm I will be video and audio-recording todays interview. Are you happy for me to go ahead and record?

If at the end of the interview you find that you are distressed or upset about what we have discussed and would like to speak with someone outside of the research team, please refer to the helplines we have provided in the Participant Information Sheet. If you do not have this to hand I can provide the helplines for you. If you would like to speak with me, there will be some time at the end of the interview where we can speak.

Before we begin the interview, I just want to clarify the definition of long-term segregation we are using as part of the study. We are adopting the legal definition of long-term segregation as stated in the Mental Health Act Code of Practice, which defines long-term segregation as:

"…*a situation where, in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation, a multi-disciplinary review and a representative from the responsible commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward or unit on a long-term basis*"

We are using this definition as it informs local NHS Trust's understanding how long-term segregation is defined. We are aware that the definition can be interpreted in different ways, however the purpose of the present interview is to explore good practice of the use of long-term segregation, as defined above, with autistic people with learning disabilities. We are interested in decisions around starting long-term segregation with autistic people with learning disabilities and what happens when autistic people are in long-term segregation.

Before we begin, it may be the case that you have been or are currently involved in high profile cases locally or nationally. We ask that you keep any details of these cases anonymous, and you will not be asked to provide patient identifiable information. Sharing detailed examples will be an important part of the interview, but **please do not name specific individuals (e.g. names of family members, the person you care for and/or staff members) or names and locations of services when being interviewed.** This is to ensure that anonymity and confidentiality are maintained throughout the interview process.

Demographic and role-based questions

- What is your location (i.e. county or city)?
- What is your professional role?
- Do you have any professional experience or involvement in the use of long-term segregation with autistic people?
- How long have you been practicing in your professional role?
- Has your professional role included being involved (in any capacity) in decisions around starting and/or ending long-term segregation with autistic

people, as well as what happens when an autistic person is in long-term segregation?

There will be opportunities to follow up and expand on answers to questions to elicit further information, seen here in italics.

Question one:

Could you provide a brief overview of your experiences of the use of long-term segregation with autistic people with learning disabilities?

Follow up: Do you find that there are differences in using long-term segregation with autistic people compared to neurotypical people? If so, what are these differences?

- *How do these differences affect the use of long-term segregation with an autistic person?*

Follow up: What are your views on the current use of long-term segregation with autistic people?

Question two:

Based on your experience, what factors on the unit/ward would you say influence the decision to use long-term segregation with an autistic person with learning disabilities?

Follow up: Can you give a specific example?

Question three:

What factors on the unit/ward influence decisions to end long-term segregation with an autistic person with learning disabilities?

Follow up: Can you give a specific example?

Question four:

Based on your experience, what in your opinion are the key challenges and difficulties when using long-term segregation with an autistic person with learning disabilities?

Follow up: How do these challenges affect the use of long-term segregation with an autistic person?

Follow up: Can you give a specific example?

Follow up: What broader factors on the unit/ward contribute to these challenges?

Question five:

From your experience have there been occasions when it has been difficult or challenging to meet the specific needs of an autistic person in an ATU when they have been in long-term segregation? i.e. communication needs, sensory needs, physical health needs?

Follow up: What specifically did you find made meeting these needs difficult?

Follow up: Can you give a specific example?

Follow up: Did these difficulties influence the use of long-term segregation with the autistic person/people?

Follow up: What broader factors on the unit/ward might make meeting the needs of an autistic person when they are in long-term segregation difficult?

Question six:

Based on your experience, in what ways has long-term segregation been beneficial for an autistic person with learning disabilities?

Follow up: Can you give a specific example?

Follow up: How have these benefits influenced the use of long-term-segregation with autistic people? Prompt: did it influence when long-term segregation was ended?

Follow up: Are there other benefits of using long-term segregation with an autistic person? Prompt: for the ward, staff?

Question seven:

Tell me about a time from your practice when you have encountered difficulties in the use of long-term segregation with an autistic person with disabilities.

Follow up: What specifically did you find did not go well in terms of the use of long-term segregation?

Follow up: What broader factors on the unit/ward may have contributed to things not going well in this example?

Follow up: What do you believe was the impact of this on the patient?

Follow up: What was the impact of this for you as a staff member?

Follow up: What do you think could have been done differently?

Question eight:

Tell me about an example of the use of long-term segregation with an autistic person with learning disabilities that you consider to be good practice.

Follow up: What suggested to you that this was an instance of good practice?

Follow up: What about this example specifically went well for the autistic person?

Follow up: What went well in terms of meeting the needs of the autistic person?

Follow up: What broader factors on the unit/ward may have contributed to good practice in the example you gave?

Question nine:

What do you think is important to ensure good practice in the use of long-term segregation with an autistic person with learning disabilities?

Follow up: Are there specific aspects of the wider unit/ward that you believe would be important?

Follow up: Are there specific aspects of long-term segregation itself that are important to consider?

Follow up: What is important to consider in terms of the specific needs of autistic people? e.g. sensory needs, communication needs.

Follow up: What do you think is important for staff to keep in mind when caring for an autistic person in long-term segregation?

Question ten:

Based on our discussion today, can you suggest three recommendations that could help staff move towards good practice when using long-term segregation with an autistic person with learning disabilities?

i.

ii.

iii.

Follow up: Can you give examples of the use of these recommendations?

Thank you for taking part in this interview. Once all interviews have been completed, the recommendation made by all participants will be collated sent out anonymously for feedback from all participants.

Appendix K. Parents and carers interview schedule

Interview Schedule-MDT

Draft Semi-Structured Interview Schedule – Carers/Parents

Study title: Consensus Based Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People-A Delphi Study

(Final version 1.1 – 11.11.2022)

Opening statement: Thank you for agreeing to be interviewed today to discuss autistic family members and/or autistic people you have or do care for who have been in long-term segregation (LTS). We will have up to an hour to discuss some of the key issues, possible benefits for autistic people, and aspects of good practice in this area. At the end you will be asked to provide recommendations to guide good practice in the use of LTS with autistic people with learning disabilities, that may inform future practice. If you would like to take a break at any point during the interview, please let me know and we can facilitate this. If you are finding any of the issues we discuss uncomfortable to talk about please let me know. To confirm I will be video and audio-recording todays interview. Are you happy for me to go ahead and record?

If at the end of the interview you find that you are distressed or upset about what we have discussed and would like to speak with someone outside of the research team, please refer to the helplines we have provided in the Participant Information Sheet. If you do not have this to hand I can provide the helplines for you. If you would like to speak with me, there will be some time at the end of the interview where we can speak.

Before we begin the interview, I just want to clarify the definition of long-term segregation we are using as part of the study. We are adopting the legal definition of long-term segregation as stated in the Mental Health Act Code of Practice, which defines long-term segregation as:

"…*a situation where, in order to reduce a sustained risk of harm posed by the patient to others, which is a constant feature of their presentation, a multi-disciplinary review and a representative from the responsible commissioning authority determines that a patient should not be allowed to mix freely with other patients on the ward or unit on a long-term basis*"

We are using this definition as it informs local NHS Trust's understanding how long-term segregation is defined. We are aware that the definition can be interpreted in different ways, however the purpose of the present interview is to explore good practice of the use of long-term segregation, as defined above, with autistic people with learning disabilities. We are interested in exploring the use of long-term segregation with autistic people with learning disabilities based on your experiences as parents and/or carers of autistic people who have experienced long-term segregation.

As we go through the interview, please try to avoid sharing personal details of family members. We are interested to hear specific examples, but we will not ask you to provide personally identifiable information. Sharing detailed examples will be an important part of the interview, but **please do not name specific individuals (e.g. names of family members, the person you care for and/or staff members) or names and locations of services when being interviewed.** This is to ensure that anonymity and confidentiality are maintained throughout the interview process.

Demographic questions

- What is your location (i.e. county or city)?
- What relationship do you hold with the autistic person?
- (If they are a carer) How long have you cared for them?

There will be opportunities to follow up and expand on answers to questions to elicit further information, seen here in italics.

Question one:

Can you provide a brief overview of your experiences of having had autistic family members or autistic people with learning disabilities you have or do care for in long-term segregation?

Follow up: What are your views on the current use of long-term segregation with autistic people?

Question two:

Based on your experience, what have been the key challenges and difficulties for your family member/ the autistic person you care for in terms of being in long-term segregation?

Follow up: Can you give a specific example?

Follow up: What do you believe contributed to these challenges?

Question three:

Based on your experience, in what ways has long-term segregation been beneficial for your family member/the autistic person you care for?

Follow up: Can you give a specific example?

Follow up: What specifically do you think made the use of long-term segregation beneficial for your family member or person you care for in this example?

Question four:

Tell me about a time where you believe that the use of long-term segregation with your family member/ the autistic person you care for has not gone well.

Follow up: What specifically did you find did not go well?

Follow up: What do you think contributed to the use of long-term segregation not going well in this example?

Follow up: What effect did this have on your family member/ the autistic person you care for?

Follow up: What do you think could have been done differently?

Question five:

Tell me about a time where you believe that the use of long-term segregation went well.

Follow up: What specifically went well?

Follow up: What do you think contributed to the use of long-term segregation going well in this example?

Follow up: What effect did this have on your family member/ the autistic person you care for?

Question six:

Based on your experience, what do you believe is important to consider when using long-term segregation with an autistic person with learning disabilities?

Follow up: What is important to consider in terms of the specific needs of autistic people? e.g. sensory needs, communication needs.

Follow up: What do you think is important for staff to keep in mind when caring for an autistic person in long-term segregation?

Question seven:

Based on our discussion today, can you suggest three recommendations that could help staff move towards good practice in the use of long-term segregation with an autistic person with learning disabilities?

i.

ii.

iii.

Follow up: Can you give examples of the use of these recommendations?

Thank you for taking part in this interview. Once all interviews have been completed, the recommendation made by all participants will be collated sent out anonymously for feedback from all participants.

Appendix L. Participant debrief sheet

Participant Debrief Sheet

(Final Version 1.1: 11.11.22)

Title of Study: Consensus Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People: A Delphi Study

IRAS project ID: 317686

Name of Researchers:

Ben Gilbey (student/investigator)

Dr Michael Baliousis

Dr Anna Tickle

Thank you for taking part in this study.

What is the purpose of the study?

The aim of the study is to draw on the experiences of MDT members and carers/parents on the key issues related to the use of long-term segregation (LTS) with autistic people in assessment and treatment units (ATUs) and to identify guidelines for good practice in this area.

The purpose of the study is to produce a set of guidelines that will aim to inform good practice for staff in the use of LTS with autistic people.

The study has used the “Delphi method”, where interviews were conducted with MDT members and carers/parents with experiences of the use of LTS with autistic people in ATUs, to elicit key issues and challenges in the use of LTS with autistic people with learning disabilities and to identify potential good practice guidelines.

During the interview you provided information and examples of your experience and suggested guidelines for staff in the use of LTS with autistic people in ATUs.

The guidelines were collated by the primary researcher and sent out to participants in the form of surveys, where guidelines were considered in terms of importance, and then again in terms of importance relative to the other participants responses. As a result of this process, the guidelines that reached the highest level of consensus were selected and finalised.

These guidelines will be offered as practice-based approaches to help support staff in the use of LTS with autistic people in ATUs. It is intended that this set of guidelines will be used in future research to ascertain how they may be best used in practice, and what the outcomes of their use may be for staff and autistic people. Anonymous information from interviews may also be used in further qualitative research.

If you have a concern about any aspect of this study, you can contact the research team, whose contact details are provided. If you wish to complain formally about any aspect of the process, you can do this by contacting FMHS ethics committee- ResearchEthics@nottingham.ac.uk.

If you have experienced distress or become upset by any aspect of participation in the research study and wish to speak to someone outside of the research team, please see the helplines listed at the bottom of this document. If you wish to speak to a member of the research team regarding any distress you have experienced in relation to participation in the research study, please contact one of the research team below.

Thank you for your time and contribution to this research.

Further information and contact details

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Helplines

Samaritans Nottingham, Tel: 116 123 (free), Tel: 0330 094 5717 (charges apply), Website: www.samaritans.org

NHS

NHS Emergency, 999

NHS Non-emergency, 111

Appendix M. Example items from Round One survey

Title of Study: Consensus Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People: A Delphi Study

Guidelines immediately related to direct LTS care

20. A graded step-by-step plan of how we support someone out, to reduce the risk of someone just living in LTS, and that becoming the new status quo.				
Type ‘x’ in one box below: This guideline is…				
Not important at all	Not very important	Is neither unimportant or important	Is important	Is essential

Comment:

21. Graded approach to coming out of LTS. Starting off with small changes and thinking about what might be meaningful to the patient. If there are issues like noise or sound, are there any changes that could be made to the environment that would reduce the impact of that without using LTS?
Type ‘x’ in one box below: This guideline is…

Not important at all	Not very important	Is neither unimportant or important	Is important	Is essential

Comment:

22. Ensure a stimulating an engaging environment is maintained, but it’s tailored individually.
Type ‘x’ in one box below: This guideline is…

Not important at all	Not very important	Is neither unimportant or important	Is important	Is essential

Comment:

Guidelines relating to wider service context around LTS

<table>
<tr><td colspan="5">23. Ensure all staff know LTS is a short-term situation and that it’s not a long-term solution.</td></tr>
<tr><td colspan="5">Type ‘x’ in one box below:

This guideline is…</td></tr>
<tr><td>Not important at all</td><td>Not very important</td><td>Is neither unimportant or important</td><td>Is important</td><td>Is essential</td></tr>
</table>

Comment:

<table>
<tr><td colspan="5">24. Robust formulation as to why LTS setup is beneficial for that person. Not because it’s going to be easier to manage than on the main unit. What’s the aim? What are you looking for? And how do you break it down? Including having a clear idea of what it would be like to stop LTS and how you’re going to get there.</td></tr>
<tr><td colspan="5">Type ‘x’ in one box below:

This guideline is…</td></tr>
<tr><td>Not important at all</td><td>Not very important</td><td>Is neither unimportant or important</td><td>Is important</td><td>Is essential</td></tr>
</table>

Comment:

25. Holding in mind what the purpose of the LTS and the purpose of the admission is. Thinking that this person needs to be discharged eventually. Having a plan about how we are going to get there.				
Type ‘x’ in one box below: This guideline is…				
Not important at all	Not very important	Is neither unimportant or important	Is important	Is essential

Comment:

Appendix N. Example items from Round Two survey with panellist feedback from Round One

University of Nottingham
UK | CHINA | MALAYSIA

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

Survey Round 2

(Final Version 1.1: 21.04.23)

Title of Study: Consensus Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People: A Delphi Study

Guidelines immediately related to direct LTS which consensus for inclusion has been reached

11. Good communication-making sure you know how that person communicates. Because sometimes you're behind a door and the only thing you can do with that person is communicate. So, make sure you're communicating effectively to their needs, not just thinking "Oh yeah they'll understand that" and they won't.					
	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 1				15%	85%
How you answered in round 1					X

Comments others made:

- Again, progress can't and won't happen unless the communication strengths and needs of the person are understood and implemented.
- Staff need to actively achieve this, and pick up all patient's signs of communication, verbal and none verbal. Active listening skills a must have.
- I think perhaps, similarly to how there should be a prompt/guidance on how the physical environment has sensory impact, there should be compulsory SLT review, where how the environment can impact on their communication methods is made clear.
- Again, important for all patients. This is not an LTS specific recommendation. It feels like some of what we are recommending is the routine support context which *should* be embedded throughout the ward. It may be important to draw attention to that and separate out the areas in which additional thinking is needed when someone is, or is in danger of, being supported in LTS.
- Applies equally in and out of LTS.
- The use of communication passports are essential.
- Would be covered in SLT assessment.

Guidelines immediately related to direct LTS care that require re-rating

Please reconsider your response in the context of the group response. If you wish to change your response, please place an ‘x’ in the ‘New response’ column under the rating that you feel best describes how important the guideline is. The numbers correspond to a response as below

8. A graded step-by-step plan of how we support someone out, to reduce the risk of someone just living in LTS, and that becoming the new status quo.					
	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 1			8%	23%	69%
How you answered in round 1					X
New response					

Comments others made:

- This should guide someone’s entire experience of being in LTS.
- Guidance for staff on a framework that can inform a step-by-step process that will facilitate a gradual lifting of restrictions is essential. This would assist to reduce the long-term continuance of LTS.
- This gives a goal to work towards with the patient which all can work towards to achieve a positive outcome.
- Providing a step-by-step plan is essential, to help keep the staff on track and motivated. More importantly the patient will be able to input their own wishes into the care plan and they too will have some appreciation in their care delivery.
- It is already guidance that a step-down plan is in place and that reduction of restrictive practices is considered from day one. However, the guidance on how this is made accessible, needs for further clarity for people with Autism.
- This is important in some contexts but pre-supposes that leaving LTS (in a context other than hospital discharge) is the right support package for all patients.
- Whilst a broad consensus is helpful, I would be wary about the potential risk of elevating a guideline into a ‘target’ or a KPI that could very easily slip into becoming a tick-box exercise.
- An end outcome is needed with differing stages however these stages should be variable and achievable and realistic depending on the individual.
- This is key to preventing people with ASD living long term in LTS and becoming accustomed to these conditions. Very easily done with regards to their barriers related to initiation and overwhelm from stimulus. It provides conditions for extreme avoidance, isolation and becomes maladaptive for this population of people.

Comment:

Guidelines relating to wider service context around LTS that require re-rating

Please reconsider your response in the context of the group response. If you wish to change your response, please place an 'x' in the 'New response' column under the rating that you feel best describes how important the guideline is. The numbers correspond to a response as below

1. Ensure all staff know LTS is a short-term situation and that it's not a long-term solution.

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 1	15%		31%		54%
How you answered in round 1					X
New response					

Comments others made:

- Shared understanding is key. It also applies to family, carers and external services
- Seclusion is a short-term solution. LTS is a long-term solution to enable staff to therapeutically build a relationship with a patient over the amount of time which is suited to them.
- Staff all need to be working with the patient, the main goal for ending LTS as soon as possible and when the patient is ready and able
- The duration of the segregation should not have a time restraint. It should end when the patient is able to safely re-join their peers or be moved to a different service if required. There should not be a timed approach as this could lead to more incidents which would develop trauma for the patient and the staff providing the care.
- I disagree with this as an outright statement, as it may be a long-term solution – if it reflects community provision that best meets the needs of the autistic individual.
- As long as 'short term' can mean 'until appropriate community placement' found
- Might be a longer-term solution for some people
- Consider the name, Long Term Segregation, maybe clarify the expectations and reasons of LTS rather than putting pressure on ending this when this isn't in the individuals' best interests, due to timeline issues and not personalised care aspects.

May be in the persons best interest to live in single service and whilst mixes outside of living environment (ie home of hospital or LTS), may not be able to mix within this living environment.

- Segregation appears to have lost its short terms usage.
- With formal auditing documentation in place and hourly/daily consideration for reduction.

Comment:

2. Robust formulation as to why LTS setup is beneficial for that person. Not because it's going to be easier to manage than on the main unit. What's the aim? What are you looking for? And how do you break it down? Including having a clear idea of what it would be like to stop LTS and how you're going to get there.					
	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 1			15%	23%	62%
How you answered in round 1					X
New response					

Comments others made:

- Staff need to know what the expectations are and how to respond in the event of all eventualities. How they will respond for example: if things do not go well. Further trauma for the patient and staff is the worst outcome and a clear plan needs to be put in place. Things need to be handled sensitively; the patient needs to know its ok. That even from failed attempts learning can be gained and things can still move forward. That sometimes 'its no-one's fault'
- This is so important
- We need to be honest that sometimes the benefit is to others – through risk reduction. Such honesty supports clear understanding of the trauma which LTS can represent.
- Need to be able to justify, as with all clinical decisions.
- Use of short-, medium- and long-term goals
- Covered in other statements.

Comment:

Appendix O. Example items from Round Three survey with panellist feedback from Two

Survey Round 3

(Final Version 1.1: 21.04.23)

Title of Study: Consensus Good Practice Guidelines for the Use of Long-Term Segregation with Autistic People: A Delphi Study

Guidelines directly related to LTS care that have reached consensus for inclusion in the final guidelines.

9. A graded step-by-step plan of how we support someone out, to reduce the risk of someone just living in LTS, and that becoming the new status quo.

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2				8%	92%
How you answered in round 2					X

Comments others made:

- The benefits of a step-down plan are staff know where abouts the patient is along their discharge process. Challenges along the way can be discussed and resolved before they impact the patient and their discharge from LTS. It keeps the team accountable and motivated. It provides patterns of behaviour which in turn provides risk assessments and management strategies.
- I think this should include a ‘barriers for change’ checklist, which allows and empowers staff to share anxieties about reducing restrictions, and consider possible environmental and/or resource barriers, in order to look at ways to overcome them.
- if new placement/ support package to enable return to home can be the plan for some people. Person-centred decisions need to be made re: the person returning to the ward environment and the person's communications about this, should be listened to. I think the wording would need amending for me to consider this 'important'. As it stands, it appears to assume that the person should re-join a shared ward environment. I think that assumption is not justifiable. One of our roles is to protect clients from having to conform to neurotypical assumptions about 'normal'. If this can include securing accommodation outside of the hospital then this could be 'essential' but I think is too vague at the moment. Given that recent operationalisation documents suggest that even removing someone from distressing areas of the ward for short

(but repeated) parts of a day is LTS, I think we need to be very wary about what we are recommending. I think some of the difference of opinion could be based on very different ward environments. I know from visiting others than ours is absolutely tiny. It is very hard for people to escape from others I the general ward environment.

3. **Ensure a stimulating an engaging environment is maintained, but it is tailored individually. *This can be informed by multidisciplinary team assessments.***

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2				15%	85%
How you answered in round 2					X

Comments others made:

- Without a step-down plan staff may not be aware of the appropriateness of their interactions. A patient who has just entered LTS may not want to engage with activities as they may require time to calm, settle and readjust. Patients who are more engaging and willing to work with staff are possibly closer to LTS being discontinued. This engagement is patient centred and tailored to their ability and interest.
- Agreed. I think a key focus on therapeutic environment and engagement has to be formally maintained, so people do not fall into seeing LTS observation purely as a surveillance and admin task (which can occur for a number of reasons)
- This feels essential but I am very wary about us recommending things which are already covered in the MHA code of practice (which says re: LTS "Patients should also be able to access secure outdoor areas and a range of activities of interest and relevance to the person"). Without a more specific recommendation that the individual tailoring should be informed in particular ways and not with reference to normative assumptions, I think we risk undermining our aims.

12. **Good communication-making sure you know how that person communicates. Because sometimes you are behind a door and the only thing you can do with that person is communicate. So, make sure you are communicating effectively to the persons needs, not just thinking "Oh yeah they'll understand that" and they won't.**

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel				15%	85%

answered the round 1					
How you answered in round 1					X

Comments others made:

- Again, progress can’t and won’t happen unless the communication strengths and needs of the person are understood and implemented.
- Staff need to actively achieve this, and pick up all patient’s signs of communication, verbal and none verbal. Active listening skills a must have.
- I think perhaps, similarly to how there should be a prompt/guidance on how the physical environment has sensory impact, there should be compulsory SLT review, where how the environment can impact on their communication methods is made clear.
- Again, important for all patients. This is not an LTS specific recommendation. It feels like some of what we are recommending is the routine support context which *should* be embedded throughout the ward. It may be important to draw attention to that and separate out the areas in which additional thinking is needed when someone is, or is in danger of, being supported in LTS.
- Applies equally in and out of LTS.
- The use of communication passports is essential.
- Would be covered in SLT assessment.

18. Valuing the person. Treating them with respect, giving them choices wherever possible and appropriate for the patient (i.e. making choice facilitation person-centred). That can be overlooked, and you are making the choices for them. Just a simple choice like “Do you want ice-cream, or do you want jelly?” Just simple choices mean so much. And it can be so validating to somebody.

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2		8%			92%
How you answered in round 2					X

Comments others made:

- Yes, perhaps emphasising that choice does not stop when a person enters LTS.
- this should be basic care, not an LTS recommendation

Guidelines immediately related to direct LTS care that require re-rating

Please reconsider your response in the context of the group response. If you wish to change your response, please place an ‘x’ in the ‘New response’ column under the rating that you feel best describes how important the guideline is. The numbers correspond to a response as below.

An alternative guideline based on combining guideline 2 with guideline 1 is below on page 5. Please consider this in your new response.

10. Graded approach to coming out of LTS. Starting off with small changes and thinking about what might be meaningful to the patient. If there are issues like noise or sound, are there any changes that could be made to the environment that would reduce the impact of that without using LTS?

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2	8%			31%	61%
How you answered in round 2					X
New response					

Comments others made:

- When the outside environment is over stimulating, the person in LTS can still be provided with the choice of whether they wanted to access communal areas by keeping the door open. This gives them control over when and for how long they want to access the communal areas of the ward
- Some patients may find leaving LTS daunting as they have left a predictable, tailored, highly staffed, low stimulated environment to return to the ward environment which can often be chaotic and unpredictable and scary especially for an Autist.
- I am the outlier again, I think! My rating was based on the assumption that a graded approach is necessarily the right one. We may well be able to go the whole way in one go and it would be inappropriate to require otherwise in those instances. Again, I think the wording of the recommendation needs adjusting. I can see that others are also wary about assumptions that small changes are always appropriate, so I think my different rating is linked to different interpretations of the question. If the wording were something like "if bolder more significant changes are not appropriate for the person, a graded approach to

coming out of LTS should be considered", I would agree this would be important.

Comment:

Alternative guideline based on combining guidelines 1 and 2 and incorporating panellists' comments from round 2:

<table>
<tr><td colspan="5">If bolder changes to a person's LTS are not appropriate, there should be a graded, step-by-step plan of how we support them out, to reduce the risk of someone living in LTS becoming the new status quo. The plan can include starting with small changes that are meaningful to the person. The plan should also include a "barriers to change" checklist, which enables staff to discuss concerns about reducing restrictions, consider possible environmental and/or resource barriers and discuss possible solutions to overcome them.</td></tr>
<tr><td colspan="2">Should the above alternatively worded guideline replace the original guidelines 1 and 2?

Mark an "X" in either response to the right</td><td colspan="2">Yes</td><td>No</td></tr>
<tr><td colspan="5">Type "X" in one box below

This guideline is…</td></tr>
<tr><td>Not important at all</td><td>Not very important</td><td>Is neither unimportant or important</td><td>Is important</td><td>Is essential</td></tr>
</table>

Comment:

This guideline is approaching consensus.

Guidelines 7, 8, and 9 below have been combined with guideline 4 on Page 14. Please consider this in your new response.

4. Ensuring the use of LTS is individualised to suit their needs, *wherever possible*. It has got to fit that individual.

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2				23%	77%
How you answered in round 2					X
New response					

Comments others made:

- Making realistic goals and achievable goals in the setup of LTS. For example, we cannot knock out a wall but we could paint the room to make it a more comfortable environment.
- I agree - too vague - what does this actually mean, other than a tokenistic use of the word individualised.
- I think we need to be clear re: what we are recommending: individualised in what sense? Communication environment? Physical environment? Sensory environment?

Comment:

Amended alternative guideline 15 incorporating panellist’s comments from round 2:

<table>
<tr><td colspan="5">Establish a clear, step-by-step plan of what the MDT has agreed should happen and which has been communicated to the staff team, in cases where a plan has been made and needs to be followed. This plan should be shared with the person in LTS whenever possible and should be revised according to the persons response and needs.</td></tr>
<tr><td colspan="2">Should the above reworded guideline replace alternative guideline 15?

Mark an “X” in either response to the right</td><td colspan="2">Yes</td><td>No</td></tr>
<tr><td colspan="5">Type “X” in one box below

This guideline is…</td></tr>
<tr><td>Not important at all</td><td>Not very important</td><td>Is neither unimportant or important</td><td>Is important</td><td>Is essential</td></tr>
<tr><td></td><td></td><td></td><td></td><td></td></tr>
</table>

Comment:

Consensus was reached in round 2 that guideline 17 should be replaced with a new version of the guideline. An alternative version, incorporating panellists' comments on the next page.

13. The importance of engagement and relationship building. Critical nature of being able to form a relationship with someone at that point in their life (in LTS), because that makes a massive difference.					
	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2				23%	77%
How you answered in round 2					X
Comments others made: • Developing a relationship with the person is important but also boundaries around this to support attachment issues. • I disagree about this being possible in the hospital environment. There are always staff and they can always (with the right supports) make the interactions they do have ones which enable positive relationships. I think people are hearing this quite differently to one another, leading to differing responses.					

Guidelines relating to wider service context around LTS that have reached consensus for inclusion in the final guidelines.

Guidelines 2, 3, and 4 have been incorporated into a new guideline due to similarities and based on panellist's comments from round 2. The new guideline incorporating panellists' comments on page 37.

4. Being clear about why you are using LTS, but also being clear on whether it is the least restrictive and most appropriate option for that person at that time. And coming back to and reminding yourself of why LTS was started. Is it working? And then thinking about what needs to happen next. A continual review process starting with why we made this decision, what are we looking to achieve. So that's a starting point for each review.					
	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2			7%	8%	85%
How you answered in round 2					X
Comments others made: • Again mentioned above. • Ongoing review is already in guidelines and policy? • This seems very similar to point 2 above.					

5. Staff being involved in the developanellistent of the LTS and stepdown plan, so right at the onset, they know what is expected. Staff on the ground, healthcare assistants (HCAs) and support workers. That helps them as well.					
	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2				8%	92%
How you answered in round 2					X
Comments others made: • HCAs are the majority of the time engaging with the patients and building those therapeutic relationships, so I think it's very important for them to have a say.					

- MDT, including HCA staff is vital and should permeate throughout any and all decision, action or changes made to LTS use.

6. **Ensure the use of LTS is fully staffed. For it to be successful you need to make sure you have a shift that is fully staffed. If a shift has the correct staffing levels, the stages of the step-down plan can be implemented. Therapeutically, activities are going to take place. Positive interactions are going to take place.**

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2			15%		85%
How you answered in round 2					X

Comments others made:

- This is important but also recognising not to keep utilising the same staff all of the time as this causes staff burnout.
- Staffing is essential, but is this meant to be part of this work? Unless perhaps, there is a recommendation that when wide runit staffin is impacted, those with autism and within LTS should where safely possible be prioritised to ensure that normal routines can remain, due to their importance.
- This indicates a point of failure if the unit is short staffed, better to develop fluidity in ways of working to provide the best care possible when staffing pressures present.

7. **The involvement of family. Keeping them up to date. Being open and transparent where things are difficult and being able to admit to that when encountering problems.** ***Having family input into staff's understanding of the person, for example discussing the family's understanding how the person likes to be engaged and modelling this in their care where possible. All family involvement must be considered in light of potential safeguarding history in relation to family members and the person's consent for family to be involved where this is possible.***

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2				8%	92%
How you answered in round 2					X

Comments others made:

- Hmm, instead of the MDT approach mentions above, it should be an entire stakeholder approach, this would mean it is not just internal staff, but those such as family, community providers, external agencies etc that are core to the persons history and care.

12. The training of staff on autism specifically, but then ensuring there are reflective spaces to support staff to continue with that reflection on training afterwards.

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2	8%		8%		85%
How you answered in round 2					X
New response					

Comments others made:

- Again LTS is not specifically just used for those with Autism.
- Similar to point 11

Guidelines relating to wider service context around LTS that require re-rating.

Please reconsider your response in the context of the group response. If you wish to change your response, please place an ‘x’ in the ‘New response’ column under the rating that you feel best describes how important the guideline is. The numbers correspond to a response as below.

1. Ensure all staff know LTS is a short-term situation and that it is not a long-term solution.

	Not important at all	Not very important	Is neither unimportant nor important	Is important	Is essential
How the panel answered the round 2	15%		23%	15%	46%
How you answered in round 2					X
New response					

Comments others made:

- Often LTS is a long-term solution after recognising the person cannot manage within the normal ward setting and it allows for a suitable placement to be found that can meet the needs of that person such as a single service.
- This should be patient centred and determined by their reactions/ desire to living with other peers and staff being around them constantly. Some patients who reside in LTS get discharged to single person services. Some patients who require a low stimulated environment have that facility within their property. The ending of LTS should be governed by the patient’s ability to safely reintegrate into society which is either ward based or community and not related to targets or pressures to move them out of LTS before they are ready.
- I think the wording needs to be tighter here. No doubt many who saw less importance in this statement know the clear differences between seclusion and LTS (e.g. in MHA CoP), however, I’d argue that many do not. I think “short term solution” is a bit ambiguous. Maybe seclusion is the only restriction that should be called “short-term”, but the guideline certainly needs something to state that only in exceptional circumstance should LTS be seen as a long-term solution.
- I guess ‘short-term’ is a very vague term? For some people, it’s maybe a few days. For others, it’s ‘until we have found you a home’. For me, the important thing is that this is not the forever solution. I think respondents have heard this term to mean quite different things. For me, I think it’s important that our staff know that we keep working for something better for people in LTS – however, that is actually operationalised. If by short-term we mean a specific time period then no, this is not important at all

Comment:

Guidelines 2, 3, and 4 have been incorporated into a new guideline due to similarities and based on panellist's comments from round 2. Please consider this in your new response. The new guideline incorporating panellists' comments on page 37.

This guideline is approaching consensus.

<table>
<tr><td colspan="6">**2. Robust formulation as to why LTS setup is beneficial for that person. Not because it is going to be easier to manage than on the main unit. What is the aim? What are you looking for? And how do you break it down? Including having a clear idea of what it would be like to stop LTS and how you are going to get there.**</td></tr>
<tr><td></td><td>Not important at all</td><td>Not very important</td><td>Is neither unimportant nor important</td><td>Is important</td><td>Is essential</td></tr>
<tr><td>How the panel answered the round 2</td><td></td><td></td><td>8%</td><td>17%</td><td>75%</td></tr>
<tr><td>How you answered in round 2</td><td></td><td></td><td></td><td></td><td>X</td></tr>
<tr><td>New response</td><td></td><td></td><td></td><td></td><td></td></tr>
<tr><td colspan="6">Comments others made:
• Wasn't this what was referred to in previous recommendations.
• If by this, we mean that 'the person could be well supported on the main ward with good quality of life and no increase in actual restrictions/ restraint to them' then yes essential. If we mean 'the person is not manageable on the main ward or to support them there actually leads to significantly more aversive responses to their behaviour - required to manage risks; then this is not important at all.</td></tr>
</table>

Comment:

Appendix P. Example items from final round survey

Finalised Guidelines Document with Vignettes

Good practice guidelines to support Multidisciplinary Team (MDT) members in safely implementing Long-Term Segregation (LTS) with autistic people.

Introduction

There is a need for good practice guidelines for the use of Long-Term Segregation with autistic people. This need has arisen out of the gap that exists between existing policy (e.g., The Mental Health Act 1983 Code of Practice) and clinical practice in the use of LTS with autistic people, which is highly variable between differing Assessment and Treatment Units (ATU's). Furthermore, existing policy such as the MHA 1983 Code of Practice is not informed by an understanding of the specific needs of autistic people. For example, it may in some instances be more appropriate to prolong LTS with some autistic people, as forcing a return to a busy and unpredictable ward environment would increase distress and, potentially, risk to self and others.

The following guidelines are intended as a resource for MDTs when implementing LTS with an autistic person. The guidelines were developed through a formal consensus process (Delphi) bringing together multiple stakeholder perspectives. Some guidelines are applicable to the immediate implementation of LTS, whereas others apply to the wider clinical setting around LTS. As such the guidelines have been divided into two sections:

1. Direct LTS Care Guidelines: these guidelines concern themselves with the immediate implementation of LTS, such as ensuring an engaging environment and communicating with the person effectively.

2. Wider Service Setting Around LTS Care: these guidelines are focused on the context around the implementation of LTS, such as making time for reflective practice specific to LTS or ensuring that the person's family members are involved wherever possible.

A note on representativeness:

The guidelines have been produced and developed by a panel of MDT members from a range of disciplines, which has shaped the content of the guidelines in line with their clinical contexts and experiences. Attempts were made to recruit family members of autistic people who have been in or were currently in LTS and incorporate their perspectives and experience into the guidelines. However, no family members were successfully recruited. As such, the guidelines should not be applied generically, but should be considered as a guiding tool, with their application being considered on a case-by-case basis.

Comments on introduction:

Direct LTS care guidelines

Please feel free to provide an example vignette that you think encompasses this guideline.

A graded step-by-step plan of how we support someone out, to reduce the risk of someone just living in LTS, and that becoming the new status quo.
Vignette 1 Soon after George arrived on the ward, he began to look up to another patient and imitate their behaviour, which was often violent and aggressive at specific times of day, which led to George behaving in similarly violent and aggressive ways towards others. This would often happen just after the patient had a violent incident, and George would copy the behaviour he observed. George's imitative behaviour continued for several weeks, at which point it was decided that LTS would be used with George. LTS was used with George to support him to step back from the behaviour he was engaging in and to help him understand that he did not need to imitate violent behaviour to get his needs met. LTS was used specifically to reintroduce the ward environment in a step-by-step fashion at times when George would be less likely to meet the other patient he imitated. George was then slowly introduced back into the company of the patient he would imitate at times when the other patient was settled. As such LTS was utilised with a specific aim of helping George to integrate onto the ward. Please provide examples vignette(s) here:

Comments:

3. Ensure a stimulating and engaging environment is maintained but it is tailored individually, wherever possible. This can be informed by multidisciplinary team assessments.
Vignette 1 When Simone was moved into LTS, the environment was not tailored to her own needs and interests. Simone started to become bored in LTS and began to flood the toilet by putting clothes in the toilet and the sink. When staff would try to intervene, Simone would try to physically fight them away from the toilet and sink. The team began to understand that the toilet, flooding the room, and the ensuing interactions with staff, was the only engaging activity in LTS for Simone which was thus reinforced. In response to this the team completed an assessment of Simone's needs and a plan was made to engage Simone in her preferred activities. The team then developed a daily schedule where a healthcare assistant, activity coordinator, speech and language therapist, and assistant psychologist began to go into Simone's area to support or engage with Simone in activities she enjoyed like puzzles, listening to music and

drawing. Over time Simone built up relationships with the team based on doing shared activities that she enjoyed, and eventually the team supported Simone to do her preferred activities outside of the LTS environment with the team. Consistent engagement with Simone helped her to build positive relationships with staff, which, together with tailored activities in LTS, helped to increase her quality of life.

Vignette 2

Paul had lived in a single occupancy service for 18 years before being admitted to an ATU. On reviewing the reasons for admission and the effect which changes to a long-established daily rhythm and the presence of others had on Paul, it was very clear to the MDT early on that Paul was not going to be able to tolerate being with others in the main ward environment, as he had preferred his own space for many years. As such the team decided to prepare the LTS space for Paul. To individualise LTS for Paul, the MDT replicated as much as possible his life in the single occupancy service. The team preserved as much of his routine as possible, for example by continuing the regular visits Paul would have with his family, the use of a kitchen and dining room area, as well as an area for crafts and therapeutic activities. Paul remained in this individualised LTS for the entirety of his time on the ATU, until he was discharged into a new single occupancy service.

Comments:

Please feel free to provide an example vignette that you think encompasses this guideline.

4. Ensuring the use of LTS is individualised to suit their needs, *wherever possible*. It has got to fit that individual.
Please provide examples vignette(s) here:

Comments:

Alternative guideline based on merging guidelines 3 and 4:

Ensure a stimulating and engaging environment is maintained *that meets the person’s needs*, but it is tailored individually, wherever possible. This can be informed by multidisciplinary team assessments.		
Should the above alternatively worded guideline replace the original guidelines 3 and 4? Mark an “X” in either response to the right	Yes	No

Comments:

Appendix Q. Finalised guidelines

Finalised Guideline Document

Finalised Guidelines Document with Vignettes

Good practice guidelines to support Multidisciplinary Team (MDT) members in safely implementing Long-Term Segregation (LTS) with autistic people with learning disabilities

Introduction

There is a need for good practice guidelines for the use of Long-Term Segregation (LTS) with autistic people with learning disabilities. This need has arisen out of the gap that exists between existing policy (e.g., The Mental Health Act 1983 Code of Practice) and clinical practice in the use of LTS with autistic people with learning disabilities, which is highly variable between differing Assessment and Treatment Units (ATU's). Furthermore, existing policy such as the MHA 1983 Code of Practice is not informed by an understanding of the specific needs of autistic people. For example, it may in some instances be more appropriate to prolong LTS with some autistic people, as forcing a return to a busy and unpredictable ward environment would increase distress and, potentially, risk to self and others.

The following guidelines are intended as a resource for MDTs when implementing LTS with an autistic person with learning disabilities. The guidelines were developed through a formal consensus process (the Delphi Method) bringing together multiple stakeholder perspectives. Some guidelines are applicable to the immediate implementation of LTS, whereas others apply to the wider clinical setting around LTS. As such the guidelines have been divided into two sections:

3. Direct LTS Care Guidelines: these guidelines concern themselves with the immediate implementation of LTS, such as ensuring an engaging environment and communicating with the person effectively.

4. Wider Service Setting Around LTS Care: these guidelines are focused on the context around the implementation of LTS, such as making time for reflective practice specific to LTS or ensuring that the person's family members are involved wherever possible.

A note on representativeness:

The guidelines have been produced and developed by a panel of MDT members from a range of disciplines, which has shaped the content of the guidelines in line with their clinical contexts and experiences. Attempts were made to recruit family members of autistic people who have been in or were currently in LTS and incorporate their perspectives and experience into the guidelines. However, no family members were successfully recruited. As such, the guidelines should not be applied generically, but should be considered as a guiding tool, with their application being considered on a case-by-case basis.

A graded step-by-step plan of how we support someone out of LTS, to reduce the risk of someone just living in LTS, and that becoming the new status quo.

Vignette

The team had learned from experience that somebody could become ‘stuck’ in LTS, leading to a limited quality of life and a lack of move-on options due to limited risk assessment of less restrictive environments. Max entered into LTS because the ward environment was too stimulating and Max’s behaviour when over-stimulated placed staff, other patients, and Max at risk of harm. It was also recognised that LTS replicated the environment that had been created in the placement prior to admission. Before LTS was initiated, consideration was given to how Max could be gradually reintroduced to the wider ATU from within the first week. This took careful planning to ensure opportunities were given for Max to leave LTS for increasing periods, taking part in activities such as eating a meal in the dining room, at first when it was empty, or watching the TV in a small lounge when others were not present. Planned activities were meaningful to Max and gradually increased over time. This prevented Max becoming fearful of time outside of LTS and ensured activities to break up time in LTS. It also prevented staff from becoming accustomed to not having to consider Max in the wider running and dynamics of the unit and allowed ongoing meaningful assessment and management of risk in varied environments.

Ensure a stimulating and engaging environment is maintained that meets the person's needs, but it is tailored individually, wherever possible. This can be informed by multidisciplinary team assessments.

Vignette 1

When Simone was moved into LTS, the environment was not tailored to her own needs and interests. Simone started to become bored in LTS and began to flood the toilet by putting clothes in the toilet and the sink. When staff would try to intervene, Simone would try to physically fight them away from the toilet and sink. The team began to understand that the toilet, flooding the room, and the ensuing interactions with staff, was the only engaging activity in LTS for Simone which was thus reinforced. In response to this the team completed an assessment of Simone's needs and a plan was made to engage Simone in her preferred activities. The team then developed a daily schedule where a Healthcare Assistant, Occupational Therapist, Activity Coordinator, Speech and Language Therapist, and Assistant Psychologist began to go into Simone's area to support or engage with Simone in activities she enjoyed like puzzles, listening to music and drawing. Over time Simone built up relationships with the team based on doing shared activities that she enjoyed, and eventually the team supported Simone to do her preferred activities outside of the LTS environment with the team. Consistent engagement with Simone helped her to build positive relationships with staff, which, together with tailored activities in LTS, helped to increase her quality of life.

Vignette 2

Paul had lived in a single occupancy service for 18 years before being admitted to an ATU. On reviewing the reasons for admission and the effect which changes to a long-established daily rhythm and the presence of others had on Paul, it was very clear to the MDT early on that Paul was not going to be able to tolerate being with others in the main ward environment, as he had preferred his own space for many years. As such the team decided to prepare the LTS space for Paul. To individualise LTS for Paul, the MDT replicated as much as possible his life in the single occupancy service. The team preserved as much of his routine as possible, for example by continuing the regular visits Paul would have with his family, the use of a kitchen and dining room area, as well as an area for crafts and therapeutic activities. Paul remained in this individualised LTS for the entirety of his time on the ATU, until he was discharged into a new single occupancy service, in line with his wishes and the MDT's assessment of his immediate discharge needs.

Ensure that communication is tailored to the persons communication needs both in terms of:

1. **Communicating with the person generally when they are in LTS.**

2. **Communicating the process of LTS to the person in terms of starting, going through, and ending LTS. This can include communicating the reasons for using LTS, how the team are going to support the person in LTS, and what role the person themselves can play in the process. Communication may also include information about how the person may be supported to return to the main ward, where this is an appropriate option for the person (given their needs).**

Vignette 1

Tom would become extremely angry and agitated in his weekly ward rounds when he was told that LTS was not yet ending. His risks would increase to himself and others’ following this news and he found it hard to engage with the staff team around him. During one of his named nurse sessions, Tom was becoming angry again at his lack of perceived progress out of LTS. His named nurse, who he had a very good relationship with, decided to draw out Tom’s pathway into LTS and then illustrate what the team were hoping to see as part of knowing he was ready to leave LTS. This was done with pictures and simple, familiar words and examples. Tom connected well with this and was able to start to reflect (with the help of some Comic Strip Conversations) on what he and staff were doing well, different choices he could make and started to show some insight into what he needed to work on and enjoy opportunities out of LTS.

Vignette 2

Tara arrived on the ATU in a mental health crisis having not been known to services previously. She was 28 years old and lived with her family. She had been to a special school but since finishing the college provision, hadn’t been seen by any services. On admission, it was reported to the team that Tara had good understanding of what was being said to her, but tended to use very simple, short responses. Tara became very distressed on the main ward with the busy to-ing and fro-ing of people she didn’t know, the noise levels and lack of familiarity. She tended to hit out at the other patients on the unit and was at risk from them when she tried to move or reorganise their belongings. An MDT decision was reached that Tara may be more settled and able to engage in the LTS environment while more assessments were taking place. The inpatient team had raised with the Speech and Language Therapist that they had noticed that Tara didn’t seem to follow what was being said and it was agreed a language assessment would be undertaken. The language assessment revealed that Tara’s level of understanding was greatly supported by her routine and familiar environment, so when she was in a new space, surrounded by new routines, people and things, she needed far greater support to understand and learn these than was previously realised. Once staff felt more confident around how to adapt their communication with Tara, they were able to support her to feel more confident in her new environment and develop her understanding and sense of safety.

Ensure a robust formulation is developed relating to why LTS is beneficial for the person, including whether LTS is the least restrictive and most appropriate option for this individual. It should include a clear idea of what it would be like to end LTS (if this is appropriate for the person). The formulation should also include a "Moving Forward Plan" that details how the person can be supported to be safely discharged. Reviews should focus on whether LTS is working for the person and what needs to happen next.

Vignette 1

Tony is autistic with severe learning disabilities. He was living in the community but was becoming increasingly distressed. Because Tony had limited capacity to communicate his distress, he was expressing distress through physically hurting others, himself, and damaging property. A decision was made to admit Tony to an ATU, but prior to this a thorough risk assessment and formulation was completed. The formulation highlighted that Tony did not have the skills to regulate his internal state when overstimulated and needed a low stimulus environment to implement regulation strategies. The formulation also noted that Tony found it difficult to regulate himself in the presence of others. Based on the formulation, the MDT decided that it would be appropriate to initiate LTS with Tony as soon as he was admitted to the ATU. If Tony was admitted onto the main ward, there was a risk that he would hurt himself or others. Through initiating LTS at the beginning of Tony's admission, he was able to retain some of his important routines whilst in LTS, that helped him self-regulate, and this increased Tony's capacity to engage with the MDT. Tony was therefore able to build a relationship with staff without being overwhelmed by sensory information. The use of LTS with Tony was continually reviewed throughout the use of LTS with Tony.

Vignette 2

Briony has Down's syndrome and is autistic and has been diagnosed with dementia. Briony had been living on the main ward for a long period of time without the need of LTS. However, as the ward environment shifted from quiet to very noisy with new admissions, this environment became intolerable for Briony. Briony started to become distressed in relation to the increasingly unpredictable sensory stimulation from the ward, particularly shouting from other patients who were in distress. Briony could not regulate herself in this context, and so it was decided that the more isolated environment of LTS would be beneficial for her. The formulation of LTS for Briony included understanding that the function of LTS was that it was a protected space for her, rather than primarily to reduce risk to self and/or others. Briony would go out on leave multiple times a day, but LTS was not understood as something that should end as soon as possible. Rather, the use of LTS for Briony reflected the single occupancy service that she had benefitted from in the community before admission to the ATU. The MDT continually monitored the function of LTS for Briony, evaluating the restrictions against Briony's care plan and formulation, keeping in mind how such restrictions were supportive for Briony in the ATU context. Criteria such as the 12 characteristics of Capable Environments were used to evaluate the use of LTS in Briony's care.

Maintain the engagement of the person and build a trusting relationship with them when they are in LTS. This process should consider the potential negative impact of the use of LTS when building a relationship with the person. Factors that have impacted on the person's ability to form trusting relationships should also be considered. These include attachment processes, and how problems such as fear, uncertainty, mistrust, and being separated from others when in LTS, may impact the relationship with the person when in LTS.

Vignette

Jason had experienced instability in his relationships early on in life and found it very difficult to trust staff on the ward. Jason found it very hard to let anyone near him. The MDT formulated that Jason was engaging in behaviours to maintain a distance from others, such as damaging property and acting aggressively towards staff. This made engaging Jason and forming a positive relationship challenging for him and the MDT. At times Jason was able to reflect that he did not want to assault anyone, but that he felt he had little control over his behaviour when in distress. Jason also later said that he had experienced being locked in a room at an earlier point in his life. This enabled the MDT to consider that LTS may be triggering past traumas of being rejected and locked away. The MDT therefore used creative approaches to build a positive relationship between Jason and the team in a gradual way which Jason could tolerate, and which connected with what Jason valued. For example, skittles (which Jason enjoyed playing with) were used to begin to interact with Jason, where there was a sufficient physical distance from the staff and Jason which he was comfortable enough with. Over time these interactions became more frequent until Jason's developing trust enabled him to tolerate staff being nearer to him, for example, to take physical observations when needed.

Value the person. Treat them with respect, give them choices wherever possible and appropriate for the individual (i.e. making choice facilitation person-centred). That can be overlooked when choices end up being made for them. Just a simple choice like “Do you want ice-cream, or do you want jelly?” could mean so much and can be so validating to somebody.

Vignette 1

When Danielle, who was autistic and a mild learning disability, was admitted to an ATU she struggled with the noisy and often unpredictable ward environment. Danielle’s significant trauma history also made forming trusting relationships with staff difficult, and she would often express her distress through self-injurious behaviours. This led the MDT to initiate LTS with Danielle. The team maintained a consistent approach with Danielle when in LTS. For example, they used visual communication boards so that Danielle would know what was happening that day and who was on shift. Over time, the predictability of the LTS environment helped Danielle engage more with the team, which led to her spending periods of time out of LTS. Danielle then asked if she could use LTS intermittently to “cool down”. This choice was facilitated by the MDT. Danielle discovered that periods of time in LTS could help her self-regulate, and over time she became more confident about being on the main ward safely, without the need to use LTS. By empowering Danielle with the choice to use LTS, the MDT helped her to manage her distress herself, until eventually LTS was no longer utilised. Being given even a simple choice here was used as a way of empowering Danielle to have a different, lived experience to their past trauma.

Vignette 2

Alex (Healthcare Assistant) was on observations with Bill, who was autistic, in LTS who really enjoyed listening to music. To facilitate this, Alex would use the computer in the observation room to play music that Bill enjoyed. One time when they were both listening to music through the LTS hatch, Alex looked at Bill and did a little dance to the music, and Bill then responded with his own dance. Through interacting with Bill like this and giving Bill choice of what he could listen to, Alex built up a positive relationship with Bill over time, who would request songs to listen to which would be facilitated by the team when on his observations. As such Alex was able to find a way to engage Bill in a way which was meaningful to Bill, giving him the choice of what music he wanted to listen to.

Wider Service Setting Around LTS Guidelines

Involve staff in the development of the use of LTS and stepdown plan, so right at the onset, they know what is expected. Staff on the ground, healthcare assistants (HCAs) and support workers.

Vignette 1

Stephen’s provider had served notice in light of Stephen’s increased distress which was being expressed through behaviour which physically hurt others. Stephen’s autism meant that he had limited capacity to verbalise his distress and communicate with others and would often behave in ways that hurt others in attempts to control his environment and regulate himself. The MDT’s assessment in the ATU indicated that LTS would be the most suitable environment to support Stephen. This was based on a formulation and care plan that recognised that Stephen significantly struggled tolerating the presence of others, and LTS would provide an environment that could support Stephen to build relationships with staff. Stephan was tall and had significantly physically hurt people in the past. Staff therefore initially struggled to enter LTS with Stephen, but through role modelling and working with staff to develop a plan for upskilling and supporting with compassion fatigue, the nurses and HCAs were able to develop rapport with Stephen, which increased the staff team’s confidence to work with Stephen and, in turn, Stephen’s engagement. Through sharing the care plan and formulation and a collaborative approach, staff understood what was expected of them, wider views were incorporated, and eventually Stephen was spending time with staff outside LTS, watching TV and playing games.

Vignette 2

Margo is a 43-year-old autistic woman who experiences voices telling her to hurt others. She did not feel safe in communal areas and began to reject support and refused to leave her room. An LTS space was agreed to be a more appropriate response to her needs. Margo agreed that she would like to re-join communal areas but needed this to be at a slow pace starting with accepting staff in her area, then having the door open more, going into the communal space for meals and then longer periods of time. A graded exposure plan was developed that helped Margo feel both safe and heard.

Ensure the use of LTS is fully staffed. For it to be successful you need to make sure you have a shift that is fully staffed. If a shift has the correct staffing levels, the stages of the step-down plan can be implemented. Therapeutically, activities are going to take place. Positive interactions are going to take place.

Vignette

Bob is the manager of an ATU. Knowing that one patient is utilising LTS, and being aware of significant staffing pressures across the Trust, Bob raised an SBAR with Clinical Directors, Modern Matrons and Heads of Service to agree that although 1:1 staffing was needed to support the individual in LTS, a 2:1 staffing need would be recorded on the system to enable a flexible response to the patients' needs and providing appropriate staffing for activities out of the LTS area and implementation of the step-down plan. This ensured staff were not pulled from the unit and, as a consequence, the patient was able to step-down from LTS in a timely way, meaning that in the long-term, there was a reduced staffing need.

Involve the family. Keep them up to date. Be open and transparent where things are difficult and admit to that when encountering problems. Have family input into staff's understanding of the person, for example discussing the family's understanding how the person likes to be engaged and modelling this in their care where possible. All family involvement must be considered in light of potential safeguarding history in relation to family members and the person's consent for family to be involved where this is possible.

Vignette

Caroline (Caz) is really close to her two Mums: Barbara and Tracey. Due to increased levels of distress, leading to aggression to others Caz is in hospital and supported in LTS. Barbara and Tracey are clear that Caz becomes agitated when overwhelmed. This morning Caz tore the window from its frame and used it to break the toilet bowl. Caz's parents were informed and joined the MDT to discuss how the inpatient unit could complete the works necessary to make the area safe. Barbara suggested they visit Caz and the work be completed during the visit. This was discussed at length, and it was agreed that Barbara and Tracey would visit Caz in the garden area where there is increased space and staff can support without overcrowding. The SLT would provide a social story to explain the visit including the fact that it would be outside. Tracey suggested they visit over lunch as it was sunny, and the family could have a picnic in the garden to increase the length of the visit and ensure there was enough time for estates to make the LTS area safe. The plan was risk assessed and agreed. By working together and everyone supporting each other, the plan worked well. Caz had a lovely and enjoyable visit and felt calm and settled. The work was completed, and the area made safe. Caz did not have to go into a crowded communal area and had the space she needed.

Train staff on autism specifically, but then ensure there are reflective spaces to support staff to continue with that reflection on training afterwards.

Vignette

A group of ATU staff attended bespoke autism and learning disabilities training developed by members of the wider MDT. The training was broken down into bitesize topics with specific focus in each session. Sessions were an hour long and run over several weeks. The training was built around using case reflections to highlight and support staff development and understanding as they knew the people discussed well and could relate to the points being raised to the people they supported.

Regular reflective practice specific to LTS that includes all MDT members involved in LTS, including healthcare assistants (HCAs). Discussions should cover issues specific to LTS, including restrictive practice, barriers to change, and whether LTS remains appropriate for the person being cared for in LTS. Reflective practice should help staff to maintain their moral agency and enable them to speak freely and openly, as well as mitigating against burnout, trauma and moral injury.

Vignette

With protected time for meetings or training being a well-known difficulty on inpatient units, the Sunshine Ward agreed to have specific LTS reflection sessions weekly on a Friday morning. The sessions were split into two so observations could be covered by wider MDT members and then those staff members ‘swap’ and attend the next session to ensure all staff members could attend. The session was led by the clinical psychologist who set an agenda covering all issues specific to LTS as named above. This agenda was sent out to Friday’s staff team on the Monday, ensuring that any topics staff wanted to discuss could be included. Once a month a clinician from the staff wellbeing team also attends and the focus is more trauma based. These sessions link into debrief sessions that are provided following any incidents on the ward and the same person centred, blame-free style adopted.

Consensus-based Good Practice Guidelines for the Use of Long-Term Segregation (LTS) with Autistic People.

A Delphi Study.

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

UNIVERSITY OF LINCOLN

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Background

Autistic adults in Assessment and Treatment units (ATUs) are subject to restrictive interventions such as Long-Term Segregation (LTS; Jones et al., 2021; Care Quality Commission, 2020). The disproportionate use of LTS with autistic people is often due to the inappropriate nature of the main ward environment (Malorent & Scott, 2017), which is not designed to meet the specific needs of autistic people. ATU ward environments can be noisy and busy, which can be overstimulating and distressing for some autistic people (Murphy & Mullins, 2017). LTS can be experienced by an autistic person as preferable, as it removes the overwhelming stimuli of the main ward. However, LTS can also equally be under-stimulating, and current guidelines do not inform staff on how to care effectively specifically for autistic people who may benefit from being in LTS, in comparison to the main ward. This lack of guidance arguable results in poor quality care and risks infringing human rights (Care Quality Commission, 2020).

Clinical Psychologist's unique skillset means they are well placed to develop guidance in consultation with relevant experts, to fill the gap between current LTS practice and guidance. Current guidance (i.e. The Mental Health Act Code of Practice 19830) is limited to viewing LTS as an intervention that must end as soon as possible (Department of Health [DoH], 2015), which may not be appropriate in all instances, especially for autistic people who find the main ward environment distressing.

Present Study

The aim of the present study was to develop a set of clinically informed good practice guidelines that staff could refer to when caring for an autistic person in LTS.

This was achieved using the Delphi Methodology (Barret & Heale, 2020), a consensus building method that has been effective in previous research developing clinical practice guidelines (e.g. English et al., 2020). A group of Multidisciplinary Team (MDT) members with experience in working with autistic people in LTS were recruited for the study.

Clinical Mindlines

The study was informed by the clinical mindlines paradigm (Gabbay and le May, 2011), which suggests that in clinical practice, clinicians and staff often do not consult explicit sources of knowledge and guidance, but instead develop implicit "mindlines" that are created through interactions with colleagues and form through clinical experience. As such the present study sought to harness the clinical reality of mindlines by exploring the clinical experiences of relevant experts and developing a set of flexible, contextually-based guidelines.

Study Objectives

- To produce a set of consensus-based, clinically-informed good practice guidelines.
- To supplement each guideline with clinical vignettes illustrating the guideline in practice.

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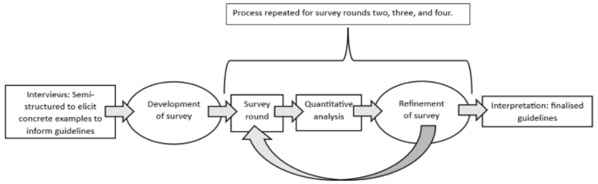
Finalised Good Practice Guidelines

Direct LTS Care Guidelines	Wider Service Setting Around LTS Guidelines
A graded step-by-step plan of how we support someone out, to reduce the risk of someone just living in LTS, and that becoming the new status quo.	Involve staff in the development of the LTS and stepdown plan, so right at the onset, they know what is expected. Staff on the ground, healthcare assistants (HCAs) and support workers.
Ensure a stimulating and engaging environment is maintained that meets the person's needs, but it is tailored individually, wherever possible. This can be informed by multidisciplinary team assessments.	Ensure the use of LTS is fully staffed. For it to be successful you need to make sure you have a shift that is fully staffed. If a shift has the correct staffing levels, the stages of the step-down plan can be implemented. Therapeutically, activities are going to take place. Positive interactions are going to take place.
Ensure that communication is tailored to the persons communication needs both in terms of: 1. Communicating with the person generally when they are in LTS. 2. Communicating the process of LTS to the person in terms of starting, going through, and ending LTS. This can include communicating the reasons for using LTS, how the team are going to support the person in LTS, and what role the person themselves can play in the process. Communication may also include information about how the person may be supported to return to the main ward, where this is an appropriate option for the person (given their needs).	Involve family. Keep them up to date. Be open and transparent where things are difficult and be able to admit to that when encountering problems. Have family input into staff's understanding of the person, for example discussing the family's understanding how the person likes to be engaged and modelling this in their care where possible. All family involvement must be considered in light of potential safeguarding history in relation to family members and the person's consent for family to be involved where this is possible
Ensure a robust formulation is developed relating to why LTS is beneficial for the person, including whether LTS is the least restrictive and most appropriate option for this individual. It should include a clear idea of what it would be like to end LTS (if this is appropriate for the person). The formulation should also include a "Moving Forward Plan" that details how the person can be supported to be safely discharged. Reviews should focus on whether LTS is working for the person and what needs to happen next.	Train staff on autism specifically, but then ensure there are reflective spaces to support staff to continue with that reflection on training afterwards.
Maintain the engagement of the person and build a trusting relationship with them when they are in LTS. This process should consider the potential negative impact of the use of LTS when building a relationship with the person. Factors that have impacted on the person's ability to form trusting relationships should also be considered. These include attachment processes, and how problems such as fear, uncertainty, mistrust, and being separated from others when in LTS, may impact the relationship with the person when in LTS.	Regular reflective practice specific to LTS that includes all MDT members involved in LTS, including healthcare assistants (HCAs). Discussions should cover issues specific to LTS, including restrictive practice, barriers to change, and whether LTS remains appropriate for the person being cared for in LTS. Reflective practice should help staff to maintain their moral agency and enable them to speak freely and openly, as well as mitigating against burnout, trauma and moral injury.
Value the person. Treat them with respect, give them choices wherever possible and appropriate for the individual (i.e. making choice facilitation person-centred). That can be overlooked when choices end up being made for them. Just a simple choice like "Do you want ice-cream, or do you want jelly?" could mean so much and can be so validating to somebody.	

Procedure: The Delphi Method


Process repeated for survey rounds two, three, and four.
Interviews: Semi-structured to elicit concrete examples to inform guidelines
Development of survey
Survey round
Quantitative analysis
Refinement of survey
Interpretation: finalised guidelines

Method

The aim of the Delphi Method is to establish consensus between a group of experts (referred to as panellists). The study recruited 14 MDT members through snowball sampling and professional networks. The panel consisted of a range of professionals from six different NHS Trusts. Experience working with autistic people in ATUs ranged from 1-39 years. The Delphi study was completed across four survey rounds, plus an initial interview round.

- Interview round: panellists were individually interviewed, and each asked to provide three good practice guidelines when caring for an autistic person in LTS.
- Round one survey: a survey was presented to panellists which contained all 41 proposed guidelines. Panellists were asked to rate each guideline in terms of importance, and to provide any written feedback on guidelines. 13 panellists responded to round one.
- The survey was amended for rounds two, three and four and personalised for each panellist, reflecting the ratings in the previous rounds, alongside the panel's overall ratings. Panellists had the opportunity to amend their initial ratings, provide further feedback, and rate alternative guidelines that emerged through the consensus-building process. 13 panellists responded to round two, 12 to round three, and 11 to round four.

Consensus was set a priori at ≥80% of panellists agreeing that a guideline is essential as indicating consensus was established, based on established convention and that nature of the topic (Diamond et al., 2014). All guidelines that met this threshold were endorsed in the finalised guidelines. Final guidelines were also supplemented by clinical vignettes based on the clinical experiences explored in the interview round, and from vignette examples requested in round four.

Results

Consensus was reached on 11 guidelines being essential (see table to the left). The guidelines fell into two broad categories, Direct LTS Care and Wider Service Setting guidelines.

Discussion

The present study produced guidance that can contribute towards improving the quality of care that autistic people receive in ATUs. The guidelines highlight how immediate and wider organisational factors must be consider together when implementing LTS with autistic people, so that LTS can be as therapeutic as possible in situations where inpatient admission is unavoidable.

References

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