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# Standing up for Myself (STORM): Adapting and piloting a web-delivered psychosocial group intervention for people with intellectual disabilities

Katrina Scior [a,*,3], Lisa Richardson [a,1,3], Michaela Osborne [a], Elizabeth Randell [b], Harry Roche [c], Afia Ali [d,2], Eva M. Bonin [e], Christine Burke [f], Jason Crabtree [g], Karuna Davies [a], David Gillespie [b], Andrew Jahoda [h], Sean Johnson [b], Richard P. Hastings [i], Rachel McNamara [b], Melissa Wright [b]

[a] Clinical Educational & Health Psychology, University College London, London, UK
[b] Centre for Trials Research, Cardiff University, Cardiff, UK
[c] Royal Mencap Society, London, UK
[d] Division of Psychiatry, University College London, London, UK
[e] London School of Economics, London, UK
[f] Foundation for People with Learning Disabilities, UK
[g] East London NHS Foundation Trust, London, UK
[h] Institute of Health and Wellbeing, University of Glasgow, Glasgow, UK
[i] CEDAR, University of Warwick, Coventry, UK

## ARTICLE INFO

## ABSTRACT

*Background:* Our STORM intervention was developed for people (16 +) with intellectual disabilities to enhance their capacity to manage and resist stigma. The current study describes the adaptation of STORM for (synchronous) on-line delivery in the context of the Covid-19 pandemic.
*Aims:* To adapt the manualised face-to-face STORM group intervention for delivery via web-based meeting platforms and to conduct an initial pilot study to consider its acceptability and feasibility.
*Methods and procedures:* The 5-session STORM intervention was carefully adapted for online delivery. In a pilot study with four community groups (N = 22), outcome, health economics and attendance data were collected, and fidelity of delivery assessed. Focus groups with participants, and interviews with facilitators provided data on acceptability and feasibility.
*Outcomes and results:* The intervention was adapted with minimal changes to the content required. In the pilot study, 95% of participants were retained at follow-up, 91% attended at least three of the five sessions. Outcome measure completion and fidelity were excellent, and facilitators reported implementation to be feasible. The intervention was reported to be acceptable by participants.

* Correspondence to: Research Department of Clinical, Educational and Health Psychology, University College London, Gower Street, London WC1E 6BT, UK.
*E-mail address:* k.scior@ucl.ac.uk (K. Scior).
[1] Present address: University of Kent, UK.
[2] Present address: East London NHS Foundation Trust, UK.
[3] Both are joint 1st authors

*Conclusions and implications:* When provided with the necessary resources and support, people with intellectual disabilities participate actively in web-delivered group interventions.

## 1. Introduction

People with intellectual disabilities face both social and health inequalities (Emerson et al., 2011; Rickard & Donkin, 2018), which place them at an increased risk of mental health problems (Emerson et al., 2011; Buckles, Luckasson, & Keefe, 2013). A contributing social factor is stigma: negative stereotypes held by society about people with intellectual disabilities, which often lead to prejudice and discrimination (Rickard & Donkin, 2018).

Addressing the mental health needs of people with intellectual disabilities through the development or adaptation of psychosocial interventions has proved successful (for reviews see National Guideline Alliance UK, 2016); Witwer et al. (2022)). However, until the advent of the Covid-19 pandemic this population had been largely neglected in e-health research (Vereenooghe, Gega & Langdon, 2017), and in the development and implementation of digital mental health interventions (Sheehan & Hassiotis, 2017). Explanations for this 'digital divide' include lower household ownership of digital devices and lower levels of access to the internet (Lussier-Desrochers et al., 2017; Ofcom, 2019), as well as limited digital skills in services supporting people with intellectual disabilities (Oudshoorn, Frielink, Nijs, & Embregts, 2020).

Increasing access to digital technology and interventions that can improve the wellbeing of large numbers of people with intellectual disabilities aligns with the need to challenge health inequalities in the UK health and social care system (NICE, 2019). A scoping review (Selick et al., 2021) of e-health care for adults with intellectual and developmental disabilities included research on medical care, therapy and psychosocial interventions delivered through remote interactions (either synchronously or asynchronously) via telephone, video, or text exchange. The review suggested that virtual methods are acceptable to this population, albeit some still had a preference to receive care in person. Challenges associated with using technology, such as internet connectivity and skill levels were noted and, in some instances, required additional support.

Engagement with the digital world by people with intellectual disabilities has gathered pace through the Covid-19 pandemic, with a galvanising of efforts to enable people to access their usual supports, activities, and social connections online (Caton et al., 2022; Chadwick et al., 2022). It is within the context of the pandemic and increased reliance on and access to the digital world that we set out to adapt for online delivery and then pilot an existing manualised psychosocial group intervention for people with intellectual disabilities.

Standing up for Myself (STORM) is a face-to-face psychosocial intervention in which a facilitator works directly with groups of young people and adults with intellectual disabilities to enhance their capacity to manage *and* resist stigma. With delivery in the context of established groups and facilitators who are known to participants, STORM provides a safe space to tackle sensitive subjects and maximises the potential for peer support. STORM was designed from the outset to be brief (4 sessions plus one follow-up session) and suitable for delivery by facilitators with a modest amount of preparation and training (without requiring specific qualifications, for more see Section 3.1). All resources are provided, including a manual, videos, and worksheets. An initial qualitative evaluation (involving 67 people across 10 groups) demonstrated the perceived benefits for participants including increased understanding (of own and others' disabilities, broader understanding of attitudes and treatment of people with intellectual disabilities), improved connections with others, drive for advocacy, increased activity and self-efficacy, and opportunity to process difficult events and emotions (Authors' own, withheld for blind review). Accessible information about STORM is available on our website: (address withheld for blind review).

The aim of the current study was to explore how the original version of STORM (designed to be delivered face to face) could be adapted to ensure it would be suitable for digital delivery, via web-based meetings; and to carry out a pilot evaluation of the adapted intervention. The objectives for the research were to examine: (a) the process of adapting the intervention; (b) recruitment and retention of participants receiving the intervention; (c) the fidelity with which the intervention was delivered; (d) the feasibility and acceptability of digital delivery of the intervention for facilitators and participants; and (e) the feasibility and acceptability of collecting outcome data online.

## 2. Methods

### 2.1. Design

Following adaptation of materials and processes from the face-to-face STORM intervention resources, an uncontrolled mixed methods pilot study where all groups received the intervention was conducted. Through qualitative methods, the views of facilitators and participants on the digital delivery of the intervention were ascertained. Outcome data were collected pre- and post- intervention using online meeting platforms and the feasibility and acceptability of this approach to data collection explored.

### 2.2. Intervention adaptation

An Intervention Adaptation Group (IAG) was established to discuss and plan what would need to be changed or added to deliver the

STORM intervention via web-based meetings. The IAG included three self-advocate advisors with intellectual disabilities (who were also involved in the initial co-design of the intervention), the patient and public involvement lead, experienced group facilitators from non-profit and education sector organisations, the intervention delivery partner ({Anonymised name for peer review},who were responsible for providing resources for the intervention, jointly responsible for training, and provided supervision to facilitators), digital inclusion experts, and members of the research team. The focus of the IAG was to work to maximise access to and engagement with the Digital STORM intervention to ensure it would be inclusive, and to consider and address potential barriers to access or engagement.

The IAG met online via Zoom over a total of four meetings, typically of 1.5 h. The meetings were co-chaired by a researcher and one of the self-advocate advisors. An agenda was prepared by the research team, with space to add any new discussion items that were brought by members. The meeting agendas covered the intervention format, and structure, as well as potential risks to acceptability and inclusion. The risks included digital technology barriers, risks to confidentiality and privacy whilst exploring sensitive topics and monitoring for emotional reactions of participants and ensuing they felt supported. On two occasions, smaller breakout groups were used to discuss agenda items in more detail. Decisions were agreed and summarised at the end of each meeting and the necessary changes implemented by adapting materials and resources. Following the pilot study, a final (5th) meeting of the IAG was held to review what was learnt through the process.

### 2.3. Participants

#### 2.3.1. Eligibility criteria for groups and participants

All participants in the pilot study had to be a part of an established group for people with intellectual disabilities that met regularly. In the context of the Covid-19 pandemic, each of the groups and their members had already done some work to move their existing meetings and activities online and so all were able to access the necessary technology (computer, tablet or phone and internet) and were accustomed to joining web-based meeting platforms (Zoom or Microsoft Teams) to participate in activities.

Participants needed to be 16 years of age or older with communication and cognitive skills in line with a mild to moderate intellectual disability. No formal assessment of intellectual disability was undertaken; rather an administrative approach to establishing this was employed (e.g., an existing diagnosis and/or use of services for people with intellectual disabilities). The session content was described in detail and sample materials shared so that facilitators could evaluate whether potential participants would be able to engage with these. Participants also needed to be able to provide informed consent.

### 2.4. Procedures

#### 2.4.1. Recruitment of participants and facilitators

Recruitment to the pilot study occurred between February and April 2021. Potential facilitators were informed about the study by our intervention delivery partner {Mencap name for peer review}, or via our research team networks.

Group facilitators were the first point of contact for recruitment as they had to be able to deliver the Digital STORM intervention to their existing group. Thereafter, they sought expressions of interest of group members by sharing information about the research using an Easy Read document (where information is presented with pictures to accompany text in simplified language and short sentences) provided by the research team. If group members expressed interest, a researcher met with the group via a web-meeting application to answer any questions. Group members met individually with a researcher to provide informed consent, which was completed by screen-sharing the consent form and obtaining a verbal response to a series of prompts on the form. At this point participants were also asked to consider participating in a focus group (jointly with members of their usual group) once the intervention had ended to provide feedback. Facilitators were initially asked to complete an agreement form related to attending training, delivering the intervention to their groups, and supporting the processes of the research.

#### 2.4.2. Collection of post-session data

Group facilitators provided feedback to the research team in two ways: (1) Through a purpose-made post-session recording form; and (2) through an interview after the final session. The post-session recording form assessed participant retention and attendance. The form included a rating for whether technical issues affected participants' engagement in the session. Ratings were on a 3-point scale; (1) no/minimal issues for participants (did not unduly impact on running the session or their engagement), (2) some issues affecting participants' engagement in the session (e.g., missed up to 15 min), or (3) significant issues affecting a participant's presence/ engagement (e.g. missed more than 15 min). Facilitators could provide additional comments regarding: (a) what went well during the session; (b) challenges to delivering the session as planned, and (c) whether anyone had become unduly upset during the session due to the session content. In case of any missing attendance and engagement data, session recordings were reviewed.

As well as delivering the intervention, all four facilitators took part in an interview one week following the last intervention session (with MO or KS) focused on the feasibility of delivering the intervention digitally. Consent for interviews with facilitators was taken at the point of the interview.

Of the 22 participants, 20 joined an online focus group one week after the intervention ended to share their experiences of taking part in the intervention. Focus groups were led by a peer researcher (HR) who was also a member of the expert advisor panel and intervention adaptation group. Following a training provided by the research team, the peer researcher took the lead in asking questions, supported by the second author. All interviews and focus groups were recorded with consent, transcribed using Otter.ai and transcripts checked for accuracy by the second author.

*2.4.3. Intervention fidelity assessment*

All Digital STORM sessions were video recorded (via Zoom/MS Teams). A fidelity checklist of core requirements was adapted from an existing instrument developed for group interventions and considering the particular social and communication needs of people with intellectual disabilities (Jahoda et al., 2013). The fidelity checklist (in the form of a Microsoft Excel spreadsheet, see supplementary files) covered (i.) adherence to the manual, (ii.) group process, and (iii.) facilitator engagement with group members. Items were rated as *definitely present/ somewhat present/ absent*. Three sessions were rated for each group. A randomised list was used to select one recording from either Session 1 or 2 and one recording from Session 3 or 4. Follow-up sessions were rated for all groups. The session videos were reviewed and rated for fidelity by KD and KS who initially independently rated the same session and reached consensus about the meaning of the three rating categories before proceeding to rate the other sessions.

*2.4.4. Collection of outcome data*

To establish the feasibility and acceptability of gathering outcome data via web-meeting platforms, the following outcome and health economics measures were administered (see Table 5 for information about scoring):

Warwick Edinburgh Mental Wellbeing Scale (Tennant et al., 2007), amended by the research team (reference period reduced from 2 weeks to 1 week; wording of some items simplified; and response scale reduced from 5 to 4-point scale).

Rosenberg Self-Esteem scale, six-item version by Dagnan and Sandhu (1999), validated for people with intellectual disabilities.

Self-Efficacy in Rejecting Prejudice, a single self-rated item: "At this moment, how confident do you feel about standing up to prejudice?", rated on a 4-point scale ('not at all confident' to 'very confident').

Reactions to Discrimination, four-item subscale of the Intellectual Disabilities Self-Stigma Scale (Ali, Strydom, Hassiotis, Williams, & King, 2008).

Sense of Social Power (Anderson, John, & Keltner, 2012), adapted four-item version of the original scale.

The above measures were rated using a 4-point Likert response scale 'never, sometimes, often, always'. The Likert scale for all items was supported by a pictorial representation of the rating scale.

To assess self-rated health and service use, the EuroQol-Youth (Wille et al., 2010) and a Client Service Receipt Inventory (Beecham & Knapp, 1992), covering a 3-months period, were completed with participants. The EuroQol-Youth was chosen for its simpler and accessible language and content which reflected the same dimensions as the adult version.

Baseline measures were administered immediately following the consent process by a trained researcher, who read items one by one, using visual supports and practice items to support understanding, and entered responses directly into the study database. Participants were able to observe the researcher register their responses. All baseline data were collected by the end of April 2021, with the intervention starting within 1–20 days of data collection. Post-intervention data were collected in the same manner 3 months from baseline (Range 10–12 weeks). All post-intervention data were collected following session 5 and before the qualitative focus groups and interviews took place (by the end of June 2021).

*2.5. Analysis*

Data on retention and attendance of participants, fidelity of the intervention delivery and feasibility of outcome data collection are summarised using descriptive statistics. Data from the qualitative interviews with facilitators and four focus groups with group members were analysed by the first and second author using framework analysis (Ritchie & Lewis, 2003). Framework analysis is a highly structured form of thematic analysis widely used in health research and useful for collaboration between multiple researchers. Using both inductive and deductive approaches to the analysis meant that themes could be identified which were closely linked to the aims of understanding the feasibility and acceptability of delivering and participating in the intervention as well as being open to unanticipated themes.

Following familiarisation with the interview transcripts, two researchers independently coded the same transcripts until any differences in coding had been discussed and resolved. Thereafter, focus group data were coded by the second author and facilitator interviews by the first author. Coding involved line-by-line reading of the transcript and applying a 'code' (e.g. 'monitoring group members' emotional responses') describing that passage of text. A working analytical framework was developed based on the study aims and further categorisation of codes, in discussion with the last author. Passages of data were then charted into the framework matrix, compared, and contrasted to interpret the data and develop themes and sub-themes.

*2.6. Ethical considerations*

Ethical approval was obtained from the first author's institutional ethics committee (Project ID 0241/005). Informed consent was obtained from participants for all parts of the research. For young people aged 16 and 17, parents were informed about the project in advance in line with usual local procedures, but these young people gave their own consent to take part.

## 3. Results

*3.1. Intervention adaptation*

Through the IAG meetings, several adaptations were decided upon that led to amendments to resources, training, structure of sessions, some content changes, and new delivery mechanisms. Resources for STORM had been collated in a digital web-based

repository called a Wiki. This was designed to enable facilitators to deliver the intervention directly from the repository (e.g., display and play videos in the right order). It was agreed with the IAG to continue with testing the Wiki for web-based delivery of the intervention, albeit with some simplification of the materials and text to be displayed. The adapted STORM manual included revised guidance on managing privacy online and how support for participants would need to be managed, however there was also some expectation that facilitators would follow their own locally developed procedures. For action planning in session 4 (see Fig. 1), templates to support this activity were included in new workbooks that were sent to all participants in advance of the sessions. The IAG group identified concerns about delivering an action planning session online, therefore more emphasis was put on identifying activities that people wanted to undertake earlier in session 3 so that facilitators could better prepare for session 4. Key adaptations are summarised in Fig. 2.

Training for facilitators was delivered to them as a group by LR and by the intervention delivery partner. This was a more structured offer than for the previous research (which was delivered more informally on a 1:1 basis by talking through the structure and content contained within the manual and how to access the associated videos via a list of links). The training consisted of 2 × 2-hour sessions. These provided an overview of the intervention and resources, guidance on its structure and manualised delivery (akin to that previously provided for face-to-face delivery), and preparation for potential challenges related to delivering the intervention via web-based meeting platforms (additional input relating specifically to the online intervention delivery mechanisms).

### 3.2. Recruitment, retention, and attendance

In total 22 people with intellectual disabilities from four groups consented to participate in the Digital STORM pilot study; one of these provided baseline data but withdrew prior to the intervention starting. Twenty-one participants were retained to the follow up data collection (see Table 2 for description of the participants). Of the four groups, one was a college-based group, and the other three were from non-profit organisations who ran social or self-advocacy groups (in the UK the latter focuses on bringing people together to speak up, campaign and influence matters affecting their lives). Each group was led by one facilitator (Table 1 for information about participating groups).

Table 3 shows the attendance and retention of participants across the STORM sessions during the pilot study. Twenty-one participants (91% of those assessed at baseline) attended three or more of the five sessions, with 14 (64%) attending all five sessions; one participant attended one session only.

Most participants (n = 18) did not miss any sessions, or more than 15 min thereof, due to technical issues. No or minimal technical

| STORM Key Messages | STORM activities |
|---|---|
| Session 1<br><br>*My learning disability\* is only one part of me.* | Videos (4 clips) followed by discussion to explore-<br><br>• what learning disability means to different people with learning disabilities<br>• what learning disability means to the participants<br>• different parts of participants identity- achievements, hobbies and what they are proud of |
| Session 2<br><br>*It's not ok for people to treat me badly. I don't have to put up with it.* | Videos (3-4 clips) followed by discussion to explore-<br><br>• the range of attitudes and actions experienced by people with learning disabilities from people without learning disabilities<br>• participants' own personal experiences of being treated positively or negatively by others |
| Session 3<br><br>*I can stand up for myself when people treat me badly.* | Videos (3-4 clips) followed by discussion to explore-<br><br>• strategies that we use to deal with negative attitudes and actions from others<br>• other ways to respond to negative attitudes and actions |
| Session 4<br><br>*I can make a plan to help me stand up for myself. People I can trust can help me with ideas.* | Begin action planning-<br><br>• review strategies that can be used to cope with or respond to negative treatment by others and discuss which one(s) suit each group member<br>• make an individual action plan to try over next few weeks<br><br>Celebration event. |
| Follow-up<br><br>*Things can get in the way of my plan. Talking to others can help me decide what to do next and not give up.* | To review and discuss-<br><br>• action plans and how they went<br>• ways to manage any barriers that arose |

**Fig. 1.** Summary of STORM key messages and activities. *The STORM intervention uses the term 'learning disability' as this is the most widely used term in the UK to refer to intellectual disability.
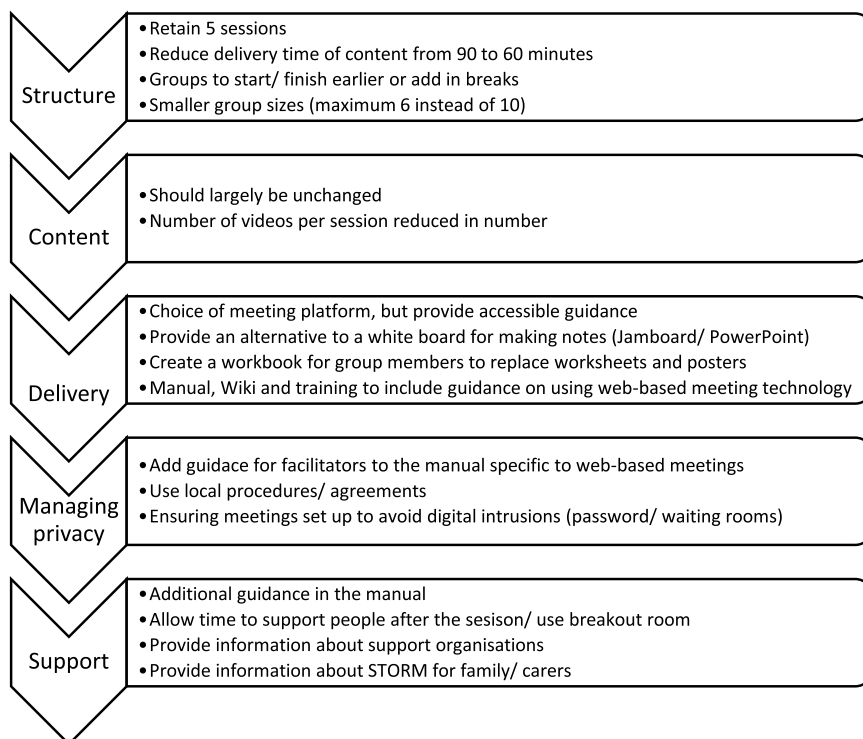
**Structure**
- Retain 5 sessions
- Reduce delivery time of content from 90 to 60 minutes
- Groups to start/ finish earlier or add in breaks
- Smaller group sizes (maximum 6 instead of 10)

**Content**
- Should largely be unchanged
- Number of videos per session reduced in number

**Delivery**
- Choice of meeting platform, but provide accessible guidance
- Provide an alternative to a white board for making notes (Jamboard/ PowerPoint)
- Create a workbook for group members to replace worksheets and posters
- Manual, Wiki and training to include guidance on using web-based meeting technology

**Managing privacy**
- Add guidace for facilitators to the manual specific to web-based meetings
- Use local procedures/ agreements
- Ensuring meetings set up to avoid digital intrusions (password/ waiting rooms)

**Support**
- Additional guidance in the manual
- Allow time to support people after the sesison/ use breakout room
- Provide information about support organisations
- Provide information about STORM for family/ carers

**Fig. 2.** Summary of intervention adaptations.

**Table 1**
Participating groups by type, size, location and facilitator characteristics.

| Group number/type | Location | Facilitator | Number of Participants |
|---|---|---|---|
| 1. Social group | Bradford, England | Project Coordinator | 6[a] |
| 2. Self-Advocacy/Social | Bridgend, Wales | Training & Development Worker | 6 |
| 3. Self-Advocacy | London, England | Learning Disabilities User Involvement Co-ordinator | 7 |
| 4. Educational (College) | Surrey, England | College Pathway Lead | 3 |
| Total | | | 22 |

[a] 1 of the 6 participants dropped out after baseline measures were taken

**Table 2**
Participant characteristics for the pilot.

| Participant characteristics | | At baseline N = 22 |
|---|---|---|
| Age in years | Median (IQR) | 34 (27–37) |
| | Range | 21–59 |
| Gender (n) | Female | 15 |
| | Male | 7 |
| Ethnicity (n) | White British/ White other | 16 |
| | Black British/ African/ Caribbean/ Other | 4 |
| | Asian British/ Asian Other | 1 |
| | Other | 1 |
| Type of school attended (n) | Mainstream | 9 |
| | Special school | 8 |
| | Both | 2 |
| | Unsure | 3 |
| Self-advocacy group attendance (n) | Yes | 15 |
| | No | 4 |
| | Unsure | 4 |

**Table 3**
Attendance of participants across the five intervention sessions (n = 21)a.

| Session number: | 1 | 2 | 3 | 4 | 5 |
|---|---|---|---|---|---|
| Group 1 (n = 5) | 5 | 5 | 5 | 5 | 4 |
| Group 2 (n = 6) | 6 | 6 | 5 | 5 | 6 |
| Group 3 (n = 7) | 5 | 6 | 6 | 5 | 3 |
| Group 4 (n = 3) | 3 | 3 | 3 | 3 | 3 |
| Total participants attending | 19 | 20 | 19 | 18 | 16 |
| **Number attending by number of sessions:** | **1 session** | **2 sessions** | **3 sessions** | **4 sessions** | **5 sessions** |
| Group 1 (n = 5) | - | - | - | 1 | 4 |
| Group 2 (n = 6) | - | - | 1 | - | 5 |
| Group 3 (n = 7) | 1 | - | 2 | 2 | 2 |
| Group 4 (n = 3) | - | - | - | - | 3 |
| Total participants attending | 1 | 0 | 3 | 3 | 14 |

[a] 1 participant provided baseline data but dropped out before the intervention began

issues were recorded for participants across most sessions (82%). Whilst 14% of all sessions involved minor issues affecting participants' presence and engagement, these were generally quickly resolved and lasted less than 15 min. Only 4% of all sessions involved significant technical problems (affecting engagement for longer than 15 min).

All 22 participants responded positively about their experience of completing the baseline measures. They felt the questionnaires would be fine for others to complete and did not note anything that could have improved their experience. Some of the responses included *"Really good, really interesting"*, *"Thought it was good and felt fab doing it"*, *"It was great, brilliant and satisfying"*, and *"I found it challenging in a good way"*.

In two of the post-intervention focus groups, participants also spoke positively about completing the questionnaires.

> *When she did the questionnaire with me. Yeah, that was good. I enjoyed that, it was just me and her. Participant from group 3*

> *I enjoyed like, [researcher], I, I enjoyed speaking to her and telling her my experiences. Participant from group 3*

### 3.3. Fidelity of intervention delivery

As can be seen in Fig. 3, the intervention was delivered with a high degree of fidelity. Over 90% of key components were observed as implemented by facilitators across most sessions, except for session 2 for group 2 (above 70% fidelity) and session 5 for groups 2–4 (above 80% fidelity). Elements judged as absent included facilitators occasionally omitting to summarise discussion points and in one case not holding an optional celebration event.

### 3.4. Qualitative analysis

The qualitative analysis is presented in two parts: findings regarding the feasibility of delivering the intervention from the facilitators' perspective, and the acceptability of the intervention from the point of view of participants. The themes are presented in Table 4 and summarised below using bold and italicized subtitles to denote main themes and within-text bold font to highlight subthemes. Verbatim quotes are used for illustration.

#### 3.4.1. Feasibility of delivering the digital STORM intervention
This theme focuses on the use of resources and support made available to enable facilitators to prepare for and deliver the



**Fig. 3.** Digital STORM fidelity ratings by session and overall Key.

**Table 4**
Summary of themes.

| Main themes | Sub-themes |
| --- | --- |
| **Feasibility of delivering the intervention** | |
| Preparing to deliver the intervention | |
| Using the intervention resources | a. Ease of using the Wiki |
| | b. Sharing resources |
| | c. Referring to the manual |
| Action planning | a. Supporting planning |
| | b. Implementing plans |
| Managing potential challenges | a. Technical difficulties |
| | b. Privacy |
| | c. Emotional responses |
| | d. Range of support |
| **Acceptability of the intervention** | |
| Intervention resources and activities | a. Videos |
| | b. Group member booklet |
| | c. Action plans |
| Threats to acceptability | a. Technical difficulties |
| | b. Maintaining privacy |
| | c. Distressing content and support |
| Recommendations | |

intervention and how challenges were managed.

### 3.4.2. Preparing to deliver the intervention

The purpose of the intervention manual was to guide facilitators in the preparation of resources, technology and for delivering each session's activities. All four facilitators gave positive reviews about the manual helping them to prepare to deliver Digital STORM (despite two indicating that they also felt there was too much information).

> *The book [manual] was really helpful. I'm much more of a paper person. So I liked having the book and I sort of scribbled notes. F2*

Facilitators were positive about the training provided; they commented on the flexibility offered in its organisation, the chance to meet other facilitators, understanding what STORM is about, and being able to ask questions. When delivering the intervention however, facilitators did not always feel fully prepared for drawing on the various resources available within the sessions.

Limited time to prepare was raised as a concern by two facilitators. Both commented on time being a scarce commodity.

> *I found myself sort of reading through the plan, sort of 5/10 min beforehand. It's just because I just literally haven't had the time to sort of sit down. F1*

All facilitators reflected on experiences of facilitating groups which had prepared them for delivering Digital STORM. One facilitator acknowledged that they felt less experienced with facilitating online and this affected how prepared they felt to deliver the intervention.

> *One, was just it was online, and us. having to learn everything myself, how to navigate sharing my screen and everything. I have been delivering online before but I think when I started the STORM, I was still new to it. So, it was more challenges on me. F3*

### 3.4.3. Using the intervention resources

This theme focuses on the use of resources when delivering the intervention. The **ease of using the Wiki** (a web platform designed as a repository for resources and an aide to delivering the sessions) whilst acceptable to one facilitator was found wanting by the other three.

> *So, when I got into the Wiki, and read through the notes, it was all familiar to me. I understood how to do it. Beforehand, you think, oh, yeah, yeah, I've got that. (…) And then when you're actually doing it and trying to engage three people at the same time, it was like, oh, okay, this is a quite a juggling act. F4*

Concerns were also noted about **sharing resources** using the screen share function. This was not optimal as facilitators found videos needed to be re-loaded or it was difficult to enlarge a video. This was more of a problem for participants joining via mobile phones than those joining using other devices.

> *I'd try and kind of set up a video and have everything prepared in advance. But you went to click on a video, and it needed to reload." F1*

When there were challenges playing the videos from the STORM Wiki, facilitators had recourse to access the same video content via links to YouTube. Having this resource helped ensure the intervention could still be delivered as intended. When it came to sharing other content, two facilitators reflected on the challenges of using web-based meeting platforms and how they tried to minimise the

anticipated problems by keeping screen sharing to a minimum.

Two facilitators were positive about the ease of **referring to the manual** for delivering the intervention sessions and activities. They said it provided a place where they could add their own notes, and group discussions were aided by drawing on the prompts and alternative approaches or phrases. This information was not on the Wiki and for this reason using the manual as a guide was preferred.

*I found that really helpful because that gave me, rather than just giving me titles, it kind of gave me questions and sentences, and [if] I felt like people weren't getting it […] there were alternative ways of wording it. F2*

### 3.4.4. Action planning

In session 4 of the intervention, group members undertake action planning, a space to begin considering how they may wish to manage or resist stigma in the future. One facilitator saw **supporting group members to plan** as very important and was very proactive for in both plan development and implementation.

*I took quite an involved approach. But we were really keen for this to not just be, yeah, you've done a programme and shove it in the drawer. Yeah, I wanted them to have a legacy from it. I want them to be able to come out in a year and say, ah, the reason I started speaking at events is because I did it on the STORM project. F3*

When it came to **implementing action plans**, proactive support when planning was important to their success, and as a result had the potential to be one of the most rewarding aspects of the intervention.

In some groups, participants did not implement any action plans and in the educational setting the timing of the holidays prevented the group from undertaking their planned project within the 4-week timeframe recommended in the manual. Other external factors such as COVID-19 restrictions also affected the implementation where group members needed support to carry out their action plans.

*But because of where [group member] lives and where I live. The restrictions meant I couldn't travel to him to meet him for any length of time. F2*

### 3.4.5. Managing potential challenges

A range of **technical difficulties** were encountered during the delivery of Digital STORM. These included poor internet connection, individuals' videos freezing, issues with Zoom account updates and logging in processes, the use of mobile phone devices to join the group sessions and devices running out of battery during the session. Many of these difficulties are not specific to the STORM intervention, but are, per say challenges of digital meetings.

*No technical problems apart from [group member's name] and every time I shared the screen, she couldn't see it. So, I had to keep sharing two to three times so that she could get it. I think because she's using her phone and maybe there's something in that maybe? F3*

Despite technical difficulties encountered, facilitators reported no or minimal impact on delivering the intervention, however it was acknowledged that these could be distracting for participants. Resolutions to technical problems were found, such as phoning people to assist them in joining the meeting, providing a re-cap, or catching up with individuals separately on any content they had missed. Some difficulties were mitigated by providing clear advice in advance or having support in place within the home from family or support staff.

All four facilitators were confident that **privacy** was maintained and managed to an acceptable level during the delivery of the intervention. Where there were extraneous people in the same space as group members during the sessions, this was understood to be necessary (e.g., for support) and was therefore accepted.

Another concern during the adaptation phase was whether facilitators in a digital environment would be able to detect and monitor **emotional responses** to the intervention content. For this reason, group sizes were kept smaller than for previous face-to face STORM intervention to ensure facilitators could see all participants on the screen at the same time. Keeping group sizes small was perceived to facilitate the monitoring of emotional responses. The larger than intended group of seven participants also reported no challenges related to monitoring participants, however they only ever had a maximum of six participants in attendance. Facilitators did not report any significant distress or negative emotional reactions by participants.

*I only had six people taking part. So, I found it okay. F2*

**A range of support** encapsulates support participants gave to each other (peer support) or received from others. Within the sessions sharing ideas to develop into action plans was one form of peer support. Beyond this there was an awareness that peers could be an alternative source of support.

*Peer support was really important.it all kind of came together when people were throwing their ideas at her. F2, during the Focus Group*

*I think that everyone's learnt actually that they can lean on other people with learning disabilities. It doesn't have to be paid staff or mums and dads. F2, during the Focus Group*

Facilitators also spoke about the support from others, this included support to join the intervention sessions.

*And it was on Teams, which he doesn't usually use. So, we had separate Teams training sessions to prepare him for that. And he smashed it. Absolutely smashed it. F2*

### 3.4.6. Acceptability of the digital intervention

This theme focuses on the participants' views of the intervention and its acceptability.

### 3.4.7. Intervention resources and activities

Two participants recognised some of the issues that facilitators had with screen sharing the **videos.** When these did not play at first, they found this to be slow and frustrating at times.

> *Like it was frustrating […] we were really struggling to watch some of them, just couldn't get them playing. G1*

The **group member booklet** was considered easy to use and a useful aid to accompany the session content, with everything in one place. The booklet was used to look at during sessions rather than to write notes. Few participants used the booklet at other times.

> *…it was everything sort of in one place. I don't think I used it outside of the outside of the sessions. But yeah, I did have it in sessions, yeah. G1*

During the focus groups, participants talked in positive terms about implementing their **action plans**, reporting an increased sense of confidence, and believing the plans would be helpful in the future.

> *But I went into Asda's myself and my mum waited outside for me. Yeah. So, I will feel that my confidence is up. I think it's been brilliant. I'm really proud of it. G2*

### 3.4.8. Threats to acceptability

Four participants reported having experienced **technical difficulties** during Digital STORM sessions. These ranged from poor internet connectivity, Zoom update requests, and low device batteries. None of the participants felt that the technical problems had negatively affected their experience of taking part or described the impact as minimal.

*I think it went well, because there were times when we were cut out because of technical issues, coming back from the previous question, but because on how the email, and all that was sent, it was easy to get back on. G4.*

Participants described the ways in which they managed the technical problems; examples included phoning the facilitator in the moment and catching up with missed content by information being posted to them.

### 3.4.9. Maintaining privacy

was discussed and generally privacy was felt to have been maintained. Where there were potential threats to privacy (e.g. the risk of a third party overhearing discussions), these were considered acceptable or well managed. Some participants described how they self-managed this, for example moving to other rooms or using headphones.

It was important to understand in the context of a digital intervention whether group members considered the **content distressing**. Five participants commented on finding some of the videos difficult to watch due to hearing about people being treated unfairly. However, they did not feel they needed additional support to process feelings associated with the material, nor did they disengage from the intervention as a result.

> *Erm the thing that I don't really like is sometimes when I watch the videos, seeing the person's reaction, how they felt after that in certain situations so, but all round is a good session, but I didn't like that really. G3*

Across the four focus groups, none of the participants felt they wanted or needed any additional **support** whilst taking part in Digital STORM. Almost half of the participants explicitly reported they had access to support if needed. As well as support from the facilitators, group members also talked about providing peer support and obtaining support from others.

> *The STORM meetings have helped me to speak up, I speak up for other people, [for example, making sure] they understand what other people are saying. G3*

> *It helped me to stand up for myself by asking other people to help me, asking the support worker to help me to stand up for myself. G3*

### 3.4.10. Benefits to participants

Three themes were identified that concern the perceived benefits of the intervention. Group members commented on an increased personal awareness, learning and growth. **Awareness** related to learning and other disabilities, and how to talk about oneself and one's life.

> *Like talking about my personal life erm.telling my stories and what I'm feeling about that. G1*

> *Learning about how to talk about the good values you've got and the bad ones. G3*

They also became more aware that they *can* stand up for themselves, as well as **learning** ways to stand up for self and others and generally managing difficult situations.

> *I learned to…be strong and say how you feel really, instead of not saying anything at all. G3*

> *For me, it was learning new things and also the different scenarios on how to stand up for myself if I was in those scenarios. G4*

Group members experienced personal **growth** through an increased confidence to stand up for themselves as well as more general confidence. This was accompanied by feelings of pride and a sense of independence.

*It gives me. me the confidence because I can easily, I can easily. if I don't like something I can always say. G1*

*I'm so proud of myself, thanks so much. All the work I've done, I'm so proud of. G3*

*Helping me to be more independent, learning me on how to be more independent. G2*

### 3.4.11. Recommendations

Three quarters of participants expressly said that they would recommend Digital STORM to others, with none saying they would not. Participants spoke about their reasons for recommending it, including what they had learnt and enjoyed about taking part.

*Because it would help other people stick up for themself. And it's very, very good to be in like a group discussing different life situations as a group. it helps. with motivation. G3*

*We all loved the STORM group, it was fantastic to learn new things. G2*

*It's really interesting to hear people's stories and it felt like it was speaking to people with learning disabilities, rather than asking other people about, you know, life for people with learning disabilities. G1*

Both facilitators and group members suggested a number of improvements, including presentation of study materials as PowerPoint slides instead of the Wiki, alongside streaming of videos via a YouTube channel. Facilitators felt action planning should be introduced earlier.

### 3.4.12. Collection of outcome and health economics data

Very high levels of data completeness were achieved for all outcome measures and across the two data collection timepoints (Table 5). Whilst 22 participants provided data at baseline, 21 provided data at follow up (this was because one participant withdrew before the intervention commencing). Except for one measure (Reactions to Discrimination, where one item was missed), 100% of completed forms were useable. Descriptive statistics for each measure are presented in Table 5 but were not subject to further analysis as the pilot study was not designed to test intervention effectiveness.

Data from questionnaires to inform a future health economics analysis were available for all 21 participants who provided both baseline and post-intervention data.

## 4. Discussion

The STORM psychosocial intervention was adapted successfully for web-based delivery in a short period of time and with minimal changes to its content. Working as a team with people with intellectual disabilities and drawing on different forms of knowledge, experience and skills were important to the success of the adaptation process. Careful consideration of accessibility issues and potential risks inherent with web-based meetings helped to mitigate the impact of these factors on the intervention implementation during the pilot study.

The initial pilot study of the intervention demonstrated good retention of research participants throughout, and facilitators were able to implement the manualised session plans with a high degree of fidelity. This supports the facilitators' accounts of the feasibility of using the materials and resources to provide the intervention via web-based meetings. Facilitators' reports also highlighted some areas where the resources require further optimisation, for example access to and playing videos and support for creating action plans. Participants found the intervention delivered via web-meetings to be acceptable, despite minor technical issues. Other risks considered during the adaptation phase were found to be feasible for facilitators to manage and acceptable to participants, namely privacy, monitoring emotional responses, and access to support if required. Participants reported benefits of engaging in the intervention online, which were in line with those observed for in-person delivery (Scior, Cooper, Fenn, Poole, Colman, Ali et al., 2022). Additionally, it is of note that peer support was a strong feature of the online delivery as it was for in-person delivery, where participants also spoke about strengthening within group connections and standing up for others (Scior et al., 2022).

The results of this pilot contribute to an emerging literature on digital interventions for people with intellectual disabilities (Oudshoorn, Frielink, Riper, & Embregts, 2021; Rawlings, Gaskell, Rolling, & Beail, 2021). The findings tentatively suggest that with support and adjustments people with intellectual disabilities can participate actively in group psychosocial interventions delivered via web-meeting platforms. Support for participants in this study included a known facilitator and in some cases support within the home environment, mirroring Selick et al.'s (2021) findings.

Digital administration of outcome measures using web meeting platforms was undertaken with 22 pilot participants at baseline and 21 at post-intervention. The results show very high levels of data completeness at both time points. Participants' narrative accounts of their experience of completing the assessments via web-based meetings with a researcher were positive, and they felt it would be acceptable for other people with intellectual disabilities to complete assessments in this way. These findings indicate that it is feasible and acceptable to collect outcome data remotely via web-based meeting platforms.

The high levels of completeness and usability of outcome data are attributed in part to detailed planning and the development of robust support processes, which ensured a positive experience for participants. It was advantageous that participants in this study had already adapted to using web-based meeting platforms. Had a larger sample been required and recruitment from a wider pool of people

**Table 5**

Outcome data at baseline and post-intervention: completeness, usability and descriptive statistics.

| | Participants (N = 22) | |
| --- | --- | --- |
| Measure: | Baseline | Post-intervention |
| **Warwick-Edinburgh Mental Wellbeing scale-** adapted, score range 0–42, higher scores indicate higher levels of mental wellbeing | | |
| Forms completed [n (%)] | 22 (100) | 21 (95) |
| Useable forms [n (% of those completed)] | 22 (100) | 21 (100) |
| Mean total score (SD) | 32.41 (6.18) | 32.66 (8.20) |
| Median (IQR) | 33 (28–38) | 35 (28–38) |
| Range | 19–40 | 15–42 |
| **Rosenberg Self-Esteem scale-** score range 0–18, higher scores indicate higher self-esteem | | |
| Forms completed [n (%)] | 22 (100) | 21 (95) |
| Useable forms [n (% of those completed)] | 22 (100) | 21 (100) |
| Mean score (SD) | 14.08 (2.80) | 14.14 (2.67) |
| Range | 7–18 | 8–18 |
| **Self-Efficacy in Rejecting Prejudice** - score range 0–3, higher scores indicate more self-efficacy | | |
| Forms completed [n (%)] | 22 (100) | 21 (95) |
| Useable forms [n (% of those completed)] | 22 (100) | 21 (100) |
| Mean score (SD) | 1.86 (1.17) | 2.00 (1.10) |
| Range | 0–3 | 0–3 |
| **Reactions to Discrimination,** adapted, score range 0–12, higher scores indicate more negative emotional reactions to stigma | | |
| Forms completed [n (%)] | 22 (100) | 21 (95) |
| Useable forms [n (% of those completed)] | 21 (95) | 21 (100) |
| Mean score (SD) | 5.52 (2.87) | 4.90 (3.14) |
| Range | 0–12 | 0–12 |
| **Sense of Social Power,** adapted - score range 0–3, higher scores indicate a higher sense of power | | |
| Forms completed [n (%)] | 22 (100) | 21 (95) |
| Useable forms [n (% of those completed)] | 22 (100) | 21 (100) |
| Mean score (SD) | 1.93 (0.68) | 2.17 (0.67) |
| Range | 0.75–3 | 1–3 |

with intellectual disabilities sought, then more barriers may have affected both overall recruitment, participation in the assessments, and quality of the data collected. However, other studies recruiting larger samples of people with intellectual disabilities to research using web-based meetings and other remote approaches during the pandemic have successfully achieved larger sample sizes and participation (Caton et al., 2022). An advantage of collecting assessment data remotely via web-based meetings for the current study was that it enabled the research team to recruit people from a wider geographical area (e.g., Wales, South East and North of England). Using web-platforms for data collection offers a pragmatic and cost-effective approach for data collection.

Several contextual aspects of the study should be born in mind when interpreting the findings. Whilst recruitment of groups and participants was successful, it is possible this was a result of the pandemic and limited opportunities to undertake usual activities. The context of the pandemic is also important in considering views on the intervention's feasibility and acceptability. The generally positive views offered by group facilitators and participants may differ outside of this context. For example, had groups been able to meet in person, a digital intervention may not have been considered acceptable to participants. The people involved in the pilot study were also already familiar with web-meeting technology; views on feasibility and acceptability may have differed had they been novices to this approach. For those new to digital technology, ongoing technical support may be essential.

The focus groups were not fully attended. In prompting discussion about group members' experiences of the intervention, it was occasionally difficult to discern whether some agreements across group members reflected a validation of a given point of view or some participants agreeing due to feeling unsure how to respond to a question. There may also have been bias created in the group context, having the facilitator present with the group and group members knowing each other prior to the group. Participants may not have felt able to be fully open about their experiences in this context (e.g. of support available or privacy concerns). Future research could build in capacity to undertake individual interviews as part of a process evaluation of the intervention.

Collection of outcome measures involved visually presenting and reading assessment questions aloud to participants. The authors recognise that this is not an approach that would be suitable to all measures and contexts. An assessment protocol was developed to avoid the risk noted by Kooijmans, Mercera, Langdon, and Moonen (2022) of clinicians and researchers routinely introducing bias by reading aloud questions from self-report questionnaires regardless of the associated guidance. Nonetheless, it is important to examine the reliability and validity of outcome measures when collected via web-based meeting platforms where researchers read questions aloud. Approaches to facilitate more independent participation in research using self-report measures also need to be advanced and accessibility addressed.

This research has shown that it is possible to adapt face-to-face group based psychosocial intervention for virtual delivery and that this approach is feasible and acceptable. It also demonstrates the potential for using the same digital technologies to support collection of outcome measures. Future research of the STORM intervention could examine effectiveness when delivered via web-meetings, possibly with a comparison of face to face modes of delivery, within a controlled design and in a range of settings. The effectiveness of web-delivered psychosocial interventions for people with intellectual disabilities more generally should also be subject to robust research.

## CRediT authorship contribution statement

**Katrina Scior:** Conceptualization, Methodology, Investigation, Formal analysis, Writing – review & editing, Supervision, Funding acquisition. **Lisa Richardson:** Project administration, Conceptualization, Methodology, Formal analysis, Writing – original draft, Visualization, Supervision. **Michaela Osborne:** Methodology, Investigation, Formal analysis, Writing – review & editing. **Elizabeth Randell:** Project administration, Conceptualization, Methodology, Writing – review & editing, Funding acquisition, Supervision. **Harry Roche:** Conceptualization, Methodology, Investigation. **Afia Ali:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition. **Eva M. Bonin:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition. **Christine Burke:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition. **Jason Crabtree:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition. **Karuna Davies:** Investigation, Formal analysis, Writing – review & editing. **David Gillespie:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition. **Andrew Jahoda:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition. **Sean Johnson:** Formal analysis, Resources, Writing – review & editing. **Richard P. Hastings:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition. **Rachel McNamara:** Conceptualization, Methodology, Writing – review & editing, Funding acquisition. **Melissa Wright:** Conceptualization, Methodology, Formal analysis, Writing – review & editing, Funding acquisition.

## Conflict of Interest Statement

There are no conflicts of interest to declare.

## Data availability

Data will be made available on request.

## Acknowledgements

*What this paper adds*

This paper adds to the growing evidence base about engaging people with intellectual disabilities in web-delivered health interventions. In the wake of the Covid-19 pandemic in particular, many interventions have been delivered online with people with intellectual disabilities but this study contributes direct data about the adaptation process and outcomes.

The paper presents data showing that people with intellectual disabilities actively engaged with the intervention, and that it was possible to gather outcome data virtually. This approach can aid study recruitment in a wider geographical area.

Working directly with adults with intellectual disabilities through the adaptation process contributed to the success of the project.

## Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.ridd.2023.104496.

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