

Digital adaptation of the Standing up for Myself intervention in young people and adults with intellectual disabilities: the STORM feasibility study

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Disclosure of interests

Full disclosure of interests: Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at <https://doi.org/10.3310/NCBU6224>.

Primary conflicts of interest: David Gillespie reports membership of the HTA Associate Board (2020), and HTA Commissioning Committee board (2021–5). Andrew Jahoda reports grants from the NIHR PHR programme (129064 and 15/126/11) and a grant from the Medical Research Council programme MR/V028596/1.

Published January 2024
DOI 10.3310/NCBU6224

Scientific summary

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Public Health Research 2024; Vol. 12: No. 1
DOI: 10.3310/NCBU6224

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Scientific summary

Background

Approximately 1.4–2% of the UK population have an intellectual disability. Individuals with intellectual disabilities face substantial social and health inequalities and are at increased risk of experiencing mental health problems. One factor compounding these inequalities is the impact of stigma, whereby individuals experience negative stereotyping, prejudice and discrimination associated with intellectual disability. Interventions that seek to reduce stigma are needed at multiple levels.

The Standing Up for Myself (STORM) programme targets the person with an intellectual disability themselves and seeks to empower them as agent of positive change. It seeks to empower individuals with intellectual disabilities to challenge stigma they face in everyday encounters, thus potentially improving well-being and reducing inequalities, alongside interventions at community and institutional/societal levels to reduce stigma.

An earlier pilot of the STORM programme showed it to be a promising intervention which could be delivered in community, third sector (i.e. 'charities' that typically provide services to achieve social goals) and education settings to existing groups of individuals with intellectual disabilities, aged 16 years and above. Some issues were highlighted which were to be addressed as part of a feasibility study with the intention of progressing to a fully powered randomised controlled trial (RCT). The start of the feasibility study coincided with the outbreak of the coronavirus disease 2019 (COVID-19) pandemic and the first national lockdown during month 6 of the original project. Following a necessary pause, the study management team saw a unique opportunity to revise the study to examine the potential of STORM as a digital intervention. Adapting STORM to make it suitable for digital delivery would allow the programme to be available to a much wider audience and potentially future-proof it in the context of the ongoing pandemic. Extensive patient and public involvement (PPI) work generated evidence in line with the National Institute for Health and Care Excellence (Evidence Standards Framework for Digital Health Technologies, 2019, www.nice.org.uk/Media/Default/About/what-we-do/our-programmes/evidence-standards-framework/digital-evidence-standards-framework.pdf) framework for digital health technologies and indicated that the creation of a digital version of STORM was important to potential future users and professionals. We, therefore, proposed to adapt the STORM programme for digital delivery to groups of individuals with mild-to-moderate intellectual disabilities. Working closely with PPI partners we planned, following adaptation of the intervention, to deliver the digital programme to four groups as part of a small pilot study. We also engaged experts on digital inclusion and learning design to ensure that the adapted digital version of STORM was optimised for engagement of people with intellectual disabilities and delivery by group facilitators with varying experience and skills in digital delivery.

Objectives

1. to adapt the existing STORM intervention for online delivery (Digital STORM), ensuring the content, number of sessions and direct contact time were the same for both STORM and Digital STORM;
2. to pilot the Digital STORM intervention in order to investigate the feasibility of recruitment to and retention of participants in Digital STORM; and adherence, fidelity and acceptability of Digital STORM, when delivered to groups of people with mild-to-moderate intellectual disabilities online;
3. to test digital administration of the study outcome and health economics measures;
4. to build on community assessments to describe what usual practice might look like for groups of

people with mild-to-moderate intellectual disabilities in the wake of COVID-19, to inform a potential future trial.

Methods

Design and procedure

Digital STORM was an adaptation of the original STORM intervention, designed for online delivery, piloted with four groups of young people and adults with mild-to-moderate intellectual disabilities.

Adaptation and pilot work took place during months 14–21 of the overall 24-month project in distinct phases of work:

1. Intervention adaptation (months 14–17)

An Intervention Adaptation Group (IAG) was established to oversee the adaptation and report progress to oversight committees. The group included all members of the PPI advisory group (people with intellectual disabilities, the independent co-chair), experienced group facilitators from third and education sector organisations (from our stakeholder group), Mencap as our intervention delivery partner, digital inclusion experts and members of the research team. The focus of this group was to maximise access to and engagement with Digital STORM to ensure it would be inclusive and to address potential barriers to access to and/or engagement with the intervention.

2. Pilot of Digital STORM (months 18–21)

The adapted intervention was then piloted with four groups ($N = 22$). Priority was given to groups that had expressed interest in participating in STORM at the point of having to pause the original study in March 2020 due to the first national coronavirus disease 2019 (COVID-19) lockdown. Of the four pilot groups, at least one would need to do some additional work to allow all its group members to access Digital STORM. This would allow us to explore ‘live’ how issues relating to access to technology, support, and provisions to ensure privacy are managed. Following delivery of the adapted digital intervention, pilot group facilitators were interviewed about their experiences to assess barriers and facilitators to implementation. Participants took part in focus groups to access their views on the intervention, the delivery mechanisms, and the intervention’s subjective impact. The focus groups were co-led by a member of the PPI advisory group and a researcher in three cases and by a researcher alone in one case and recorded.

3. Decision phase (month 22)

Oversight committees met at regular intervals throughout the adaptation and pilot phases to monitor progress. They reviewed findings from the pilot against the progression criteria and made recommendations to the National Institute for Health and Care Research (NIHR) regarding the potential for a future funding application.

Inclusion and exclusion criteria

Groups from third and education sector organisations were included where they had a willing facilitator and organisational support in place, were meeting or restarting meetings as a group for at least 3 further months and were willing to replace five of their meetings with Digital STORM. Groups needed at least three and no more than eight members with intellectual disabilities to participate. Groups were excluded if they were run as part of the National Health Service, or if some of their regular members declined taking part in Digital STORM and if it was not possible to find alternative meeting times for those who wanted to participate.

Individual participants were included if they were aged 16 years or older, had mild-to-moderate intellectual disabilities, capacity to provide informed consent, were able to complete the outcome measures and could engage with the intervention in English. They needed to be a member of an established (educational, activity, social or self-advocacy focused) group; to have access to the internet, a device to join web meetings, and support to access web-based meetings when needed. Participants were excluded from the research if they did not provide consent.

Intervention

Adaptation of the STORM intervention for delivery using web-based video meetings (Digital STORM), consisting of four weekly 90-minute sessions and a 90-minute follow-up session (delivered around 4 weeks after session four). An intervention manual and a Wiki (a web platform designed as both a repository of intervention resources and an aide to delivering session content) was provided to facilitators.

Outcomes

The primary outcome of the adaptation phase was the feasibility and acceptability of delivering STORM to groups in a web-delivered format (Digital STORM). Secondary outcomes of the adaptation phase were the feasibility of remotely collecting outcomes, health economics and process data and the description of 'Usual practice', that is, activities usually undertaken within the group setting, in a changed service delivery context.

Analyses

Pilot data (baseline demographics, responses to outcome measures, adherence and fidelity ratings) were described descriptively. The feasibility of economic evaluation was assessed using completion rates of included measures [Service Information Schedule (SIS), EuroQol-Youth version, and Client Service Receipt Inventory]. Intervention costs were calculated using SIS data.

Qualitative interviews and focus groups were conducted to explore barriers and facilitators to participation in the intervention. Interview and focus group transcripts were analysed thematically using Framework analysis; a sample of transcripts was double coded.

Progression criteria were included to determine suitability for moving to a future trial of Digital STORM.

Results

The STORM intervention was successfully adapted for online delivery (objective 1). The IAG addressed issues such as access to the digital intervention, engagement with it and potential risks to managing participant privacy. Minor adjustments were made to the STORM intervention to allow for digital delivery. Content was slightly streamlined to ensure each session could be covered within the 60-minute sessions. Resources were created to support participation in online group work (for participants) and for running sessions (for facilitators). A revised intervention logic model for Digital STORM was also created.

Digital STORM was both feasible and acceptable when delivered to groups online (objective 2). Targets for recruitment into the pilot of Digital STORM were met with 4 groups taking part and 22 participants providing informed consent, 1 of whom dropped out before starting the intervention. There was good attendance across sessions (median attendance 5 out of 5 sessions, with 20 of 21 participants attending 3 or more sessions) and the majority of participants missed no more than 15 minutes of any one intervention session due to technical difficulties. Accordingly, there was a strong indicator of feasibility for progression to a future trial. There was also a strong indicator for the acceptability of Digital STORM. Facilitators found the recording of sessions acceptable and over 90% of the core intervention requirements were met in full.

Feasibility and acceptability were also examined through interviews (with facilitators) and focus groups (with participants). Resources supported facilitators' delivery of sessions though some reported challenges when playing and sharing videos in online meetings and with trying to co-ordinate moving between video sharing via the STORM Wiki platform, the manual and operating the meeting platform.

Feasibility of administering study outcome measures was also demonstrated (objective 3). Participants completed outcome measures via web-based platforms at baseline and post intervention. This enabled the research team to recruit from a wider geographical area than would have been possible using face-to-face data collection methods. Data completeness was very high – only one response was missing across all measures. Similarly, data completeness for economic evaluation was very good with no barriers to future data collection identified. Group members' experience of completing measures was positive and they felt positive about the digital approach as a method for data collection in future.

Finally, it was determined that many organisations delivering group sessions had made the transition to online delivery and were running virtual groups. This supports the possibility of including a control arm that described 'usual practice' as part of a future trial (objective 4).

Conclusions

The STORM digital adaptation and pilot was a well-delivered package of work. Results evidence that all progression criteria were achieved in full. Oversight committees therefore recommend progression to a full trial.

Strengths and limitations

The key strength of this work was the ability of the team to work flexibly and creatively to adapt to the changing situation of the pandemic. Involvement of experts by experience meant the rationale for creating a digital version of STORM was supported by all stakeholders and the accessibility of the processes and resources was considered carefully from a user perspective.

A number of limitations need noting. These include the small sample size for the pilot; long-term retention was not established; those taking part all did so with the knowledge they would receive the intervention, thus the ability to randomise was not confirmed; the video sharing platform was not optimal – other approaches might have worked better; qualitative work could not capture the views of all those who took part in the pilot.

Study registration

This study was registered as ISRCTN16056848.

Funding

This award was funded by the National Institute for Health and Care Research (NIHR) Public Health Research programme (NIHR award ref: 17/149/03) and is published in full in *Public Health Research*; Vol. 12, No. 1. See the NIHR Funding and Awards website for further award information.

Public Health Research

ISSN 2050-4381 (Print)

ISSN 2050-439X (Online)

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This report

The research reported in this issue of the journal was funded by the PHR programme as project number 17/149/03. The contractual start date was in October 2019. The final report began editorial review in March 2022 and was accepted for publication in November 2022. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PHR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

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