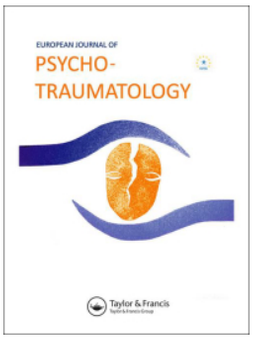

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CLINICAL RESEARCH ARTICLE

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Co-production of *Spring PGD*: a guided digital therapy for prolonged grief disorder (PGD)

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ABSTRACT

Background: Prolonged Grief Disorder (PGD) affects a significant minority of bereaved individuals, leading to persistent emotional distress and functional impairment for six months or more. While cognitive behavioural therapy (CBT) with a grief specific focus is effective, access is limited due to the resource demands of in-person therapy. Guided digital therapies offer a promising alternative, but research on their use in the UK remains limited.

Objective: This study aimed to develop a guided digital therapy for PGD using a co-production approach that engaged both individuals with relevant lived experience and professionals specialising in grief-related mental health. The goal was to design a user-centred, evidence-informed intervention to improve access to PGD treatment.

Method: The development process followed a multi-stage approach. First, rapid literature reviews were conducted to assess existing evidence on in-person and digital therapies for PGD. Second, qualitative interviews were held with stakeholders, including individuals with lived experience of PGD and professionals in grief and/or digital interventions. The interviews gathered opinions on intervention content, structure, and delivery. Inductive thematic analysis was used to identify key themes, which informed the intervention design.

Results: Five key themes emerged: (1) acceptability of digital interventions for PGD, (2) challenges in adjusting to loss and finding meaning, (3) optimal timing for therapy, (4) the need for simplicity in intervention delivery, and (5) strategies for effective user engagement. These insights guided the development of a practical, accessible, and engaging intervention.

Conclusions: The co-production process led to the development of a guided digital therapy for PGD, incorporating perspectives from both individuals with lived experience and professionals. This study highlights the importance of cultural sensitivity, user engagement, and simplicity in digital intervention design. Findings will inform the next steps in evaluating and refining the intervention to enhance access to PGD treatment in the UK and beyond.

Coproducción de *Spring TDP*: una terapia digital guiada para trastorno de duelo prolongado (TDP)

Antecedentes: El Trastorno de Duelo Prolongado (TDP) afecta una minoría significativa de individuos en duelo, llevando a un malestar emocional persistente y discapacidad funcional durante seis meses o más. Si bien la terapia cognitiva conductual (TCC) centrada en el duelo es eficaz, su acceso es limitado debido a las demandas de recursos de la terapia presencial. Las terapias digitales guiadas ofrecen una alternativa prometedora, pero investigaciones de su uso en el Reino Unido sigue siendo limitada.

Objetivo: Este estudio buscó desarrollar una terapia digital guiada para el TDP usando un enfoque de coproducción que involucró tanto a personas con experiencia vivida relevante como a profesionales especializados en salud mental relacionada con el duelo. El objetivo fue diseñar una intervención centrada en el usuario, informada en la evidencia para mejorar el acceso al tratamiento del TDP.

Método: El proceso de desarrollo siguió una aproximación de múltiples etapas. Primero, se llevaron a cabo revisiones rápidas de la literatura que evaluaron evidencia existente en terapias presenciales y digitales para el TDP. Segundo, se llevaron a cabo entrevistas cualitativas con las partes interesadas, incluyendo individuos con experiencia directa en TDP y profesionales en intervenciones de duelo y/o digitales. Las entrevistas recolectaron opiniones en el contenido, la estructura, y la implementación de la intervención. Se utilizó un análisis temático inductivo para identificar los temas clave que fundamentaron el diseño de la intervención.

Resultados: Cinco temas claves emergieron: (1) aceptabilidad de las intervenciones digitales para el TDP, (2) dificultades para adaptarse a la pérdida y encontrar significado, (3) momento óptimo para la terapia, (4) la necesidad de simplificar la implementación de la

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PALABRAS CLAVE

Trastorno de duelo prolongado; duelo; digital; TCC; *Spring*

HIGHLIGHTS

- This study employed a co-production approach, with input from individuals with lived experience of PGD and professionals in grief-related mental health to design a novel user-centred guided digital intervention – *Spring PGD*.
- Inductive thematic analysis of interviews identified five key themes, including the acceptability of digital therapy, challenges in adjusting to loss, and the importance of simple and engaging content delivery for better user engagement.
- The intervention was designed with a focus on accessibility and simplicity, ensuring it could be easily used by individuals with varying levels of digital literacy and tailored to the diverse needs of people experiencing PGD.

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intervención, y (5) estrategias para una participación efectiva del usuario. Estos hallazgos guiaron el desarrollo de una intervención práctica, accesible, y atractiva.
Conclusiones: El proceso de coproducción llevó al desarrollo de una terapia digital guiada para TDP, incorporando las perspectivas, tanto de las personas con la experiencia vivida como de los profesionales. Este estudio subraya la importancia de la sensibilidad cultural, participación del usuario y simplicidad en el diseño de la intervención digital. Los hallazgos orientarán los siguientes pasos en la evaluación y perfeccionamiento de la intervención para mejorar el acceso al tratamiento del TDP en el Reino Unido y en otros países.

1. Introduction

While most individuals experience natural adjustment following bereavement, an estimated 9% go on to develop prolonged grief disorder (PGD), a condition characterised by persistent emotional distress and significant functional impairment lasting six months or more (Lundorff et al., 2017; World Health Organization, 2018; Yuan et al., 2024). PGD is marked by an intense preoccupation with the deceased, accompanied by significant emotional pain, which can severely disrupt personal, social, and occupational functioning (World Health Organization, 2018). Epidemiological studies suggest that a higher prevalence of PGD may be associated with certain types of loss, such as sudden or traumatic death, and particularly close relationships, including the loss of a child (Szuhany et al., 2021; Yuan et al., 2024). The importance of addressing PGD is underscored by its association with negative outcomes such as increased suicide risk, poor social and occupational functioning, sleep disturbances, and physical health issues (Holland et al., 2016; Szuhany et al., 2021). These consequences not only contribute to considerable personal suffering but also have broader societal and economic implications (Holland et al., 2016; Lundorff et al., 2017; Szuhany et al., 2021).

Although cognitive behavioural therapy (CBT) with a grief specific focus has demonstrated efficacy its availability remains limited (Andersson & Titov, 2014; Hewison et al., 2020; Pearce et al., 2021). The intervention is resource-intensive, requiring specially trained therapists and significant time and financial investment, which constrains access to care. The gap between the demand for CBT with a focus on grief and the availability of evidence-based therapy creates a challenge in providing timely intervention (Hewison et al., 2020; Pearce et al., 2021).

One promising solution is the adaptation of evidence-based psychological therapies into digital formats, an approach that gained prominence during the COVID-19 pandemic and has since become widely advocated (Witteveen et al., 2022). This method offers a potentially cost-efficient and accessible alternative to traditional in-person therapy. Research has shown that incorporating guidance from a therapist into digital interventions significantly improves outcomes by helping users maintain engagement, receive personalised feedback, and stay motivated (Andersson & Titov, 2014; Lewis et al., 2019). Known as *guided* digital therapy, this model of delivery allows users to work through structured materials at their own pace while benefiting from specialist support. By reducing the need for extensive therapist input, guided digital therapy provides a more scalable, accessible, and efficient alternative to traditional therapy, with the potential to ease the strain on mental health services and make evidence-based therapy more widely available.

Thirteen randomised controlled trials (RCTs) have evaluated both guided and unguided digital therapies for grief related mental health problems (Brodbeck et al., 2019; Eisma et al., 2015; Kersting et al., 2011; Litz et al., 2014; van der Houwen et al., 2010; Wagner et al., 2006, 2022). A systematic review synthesised the findings of seven of these studies, which specifically focused on CBT-based interventions (Wagner et al., 2020). These trials, including 1,257 participants, revealed moderate to large effects on grief ($g = .54$) and traumatic stress symptoms ($g = .86$), with a smaller effect on depression ($g = .44$). Notably, these effects remained stable over time. Despite the promising results, the review noted the limited number of studies and insufficient statistical power for moderator analyses, underscoring the need for further research.

More recent RCTs have also yielded some promising results. Dominguez-Rodriguez et al. (2023) evaluated an unguided digital intervention combining CBT, mindfulness, and positive psychology in 114 participants (Dominguez-Rodriguez et al., 2023). The intervention significantly reduced symptoms of depression, hopelessness, grief, anxiety, and suicide risk. However, dropout was high, with only 39.5% completing the intervention and 60.5% completing the waitlist period. Similarly, Reitsma et al. (2023) conducted an RCT with 65 participants, demonstrating significant reductions in disturbed grief, post-traumatic stress disorder (PTSD), and depression for those receiving unguided digital CBT compared to waitlist controls (Reitsma et al., 2023). However, a 40.6% dropout rate was observed, with participants citing the lack of therapist support as the primary reason for discontinuation.

For guided interventions, Treml et al. (2021) evaluated a five-week digital CBT writing intervention for individuals bereaved by suicide, with a sample of 58

participants (Kaiser et al., 2022), finding significant improvements in PGD and depressive symptoms compared to a waitlist control, with large effect sizes sustained over time. However, no significant effect was found for general psychopathology (Treml et al., 2021). Lenferink et al. (2023) conducted an RCT with 40 participants, evaluating digital CBT for PGD following traumatic loss (Lenferink et al., 2023). This trial also found statistically significant reductions in prolonged grief, traumatic stress, and depression. Similarly, Kaiser et al. (2022) reported a clinically significant reduction in PGD symptoms in a sample of 87 individuals bereaved by cancer (Kaiser et al., 2022). However, participants were predominantly female and highly educated, which limits the generalisability of their findings to the broader bereaved population. Brodbeck et al. (2019) conducted a larger RCT with 110 participants, evaluating a guided intervention for older adults following spousal bereavement or separation/divorce (Brodbeck et al., 2019). Although the intervention showed promise, 77% of participants were separated, with only 23% widowed.

Despite promising findings, important gaps remain in the development and evaluation of guided digital interventions for PGD. Many existing interventions target specific subgroups, such as older adults or those bereaved by cancer or suicide, limiting their applicability to the wider bereaved population. Additionally, high dropout rates in some studies suggest that current interventions may not be optimally engaging or acceptable to users, though it is important to note that discontinuation does not necessarily reflect a negative experience. Moreover, no RCTs have yet been conducted to evaluate an English-language intervention for PGD, and all identified studies have been conducted outside of the UK, highlighting a significant gap in research within the UK context. Differences in bereavement rituals, grief-expression, and societal attitudes towards mourning can influence how interventions are received and how effective they are. As a result, interventions developed in one country may not automatically translate to another. Given these challenges, there is an urgent need to design and evaluate digital interventions specifically for the UK context, ensuring they are relevant, accessible, and appropriate for a diverse range of users.

Building on our success in developing an evidence-based guided digital therapy for PTSD (Bisson et al., 2023; Lewis et al., 2013; Lewis et al., 2017), we aimed to develop an intervention based on similar principles for PGD. In a multi-site RCT conducted across Wales, England, and Scotland, our digital intervention for PTSD demonstrated non-inferiority to gold-standard in-person therapy and has been provisionally recommended by the National Institute for Health and Care Excellence (NICE) guidelines (Bisson et al., 2023; NICE, 2023). These achievements have facilitated the integration of the intervention within the National Health Service (NHS) in the UK, with plans underway to expand its implementation. This experience positions us to develop and evaluate an intervention based on similar principles for PGD.

2. Method

2.1. Study aim and design

The aim of this study was to develop an optimally configured guided digital therapy for PGD. A co-production approach was employed to ensure meaningful collaboration between researchers and stakeholders. The process involved active participation from individuals with lived experience of PGD and professionals with expertise in grief-related mental health. The study design was guided by the Medical Research Council (MRC) framework for the development of complex interventions (Skivington et al., 2021), ensuring that the intervention was both evidence-informed and user-centred. An iterative approach was used to refine the intervention based on ongoing feedback and stakeholder engagement. Ethics and regulatory approvals were secured from the Wales Research Ethics Committee 2 (IRAS ID: 287681). All participants provided written informed consent.

2.2. Literature review

A series of rapid literature reviews were conducted through targeted searches of academic databases and other relevant sources to synthesise current evidence on psychological therapies for PGD. The reviews focused on both in-person and digital delivery formats and explored digital interventions for other mental health conditions, identifying best practices, common challenges, and effective delivery methods. The findings provided key insights to inform the development of the guided digital therapy.

2.3. Synthesis of evidence

To ground the co-production process in the latest empirical evidence and established best practices, key findings from the literature reviews were synthesised into a structured and accessible document, summarising therapeutic approaches, delivery methods, and evidence of efficacy for PGD interventions in both traditional and digital formats. This document was designed to be easily reviewed by stakeholders prior to their interviews, ensuring they were well-informed and equipped to contribute meaningfully.

2.4. Stakeholder selection and recruitment

Two primary groups of stakeholders were identified for the co-production process: individuals with lived

experience of PGD and professionals with expertise in grief and/or digital interventions. Participants with lived experience were purposively sampled from charitable organisations and the National Centre for Mental Health (NCMH) cohort of volunteers who had consented to be contacted about research (https://www.ncmh.info/). Professionals were recruited through snowball sampling (Biernacki & Waldorf, 1981), with initial contacts from clinical and academic settings, as well as charities. This approach ensured a diverse range of perspectives, capturing insights from both those directly affected by PGD and professionals with relevant expertise. The sample size was guided by the principle of information power (Malterud et al., 2016), ensuring that the dataset was sufficiently rich and comprehensive to address the study objectives.

2.5. Inclusion and exclusion criteria

For the lived experience stakeholders, inclusion criteria specified individuals aged 16 or over, with no upper age limit, who self-reported lived experience of mental health problems characteristic of PGD after a bereavement. Participants did not need to currently meet criteria for PGD or have a formal diagnosis. The exclusion criteria for this group included an inability to understand spoken and/or written English, as well as an inability to provide valid informed consent.

For professional stakeholders, inclusion criteria required expert knowledge of PGD and/or experience of delivering therapy for the disorder, or expert knowledge of digital therapy and/or experience of delivering therapy in that format. The exclusion criteria for professional stakeholders were the same: an inability to understand spoken and/or written English, and an inability to provide valid informed consent.

2.6. Co-production process

Stakeholders were invited to participate in qualitative interviews via video calls, where they were asked to provide opinions on the content, structure, and delivery of the proposed digital intervention, guided by a pre-defined topic guide. To ensure participants were well-informed and able to offer evidence-based input, the evidence synthesis document was shared with them in advance. Written informed consent was obtained from all participants, and as a token of appreciation, individuals with lived experience were compensated £10 for their time. The interviews followed a semi-structured format, allowing participants to share their views freely while covering key topics, such as usability, content, accessibility, and user engagement. All interviews were audio-recorded with consent to ensure accurate capture of participant input. Audio recordings were subsequently transcribed for qualitative analysis.

2.7. Qualitative analysis

We conducted inductive thematic analysis following the six-phase approach outlined by Clarke and Braun (2017). The analysis was data-driven, allowing themes to emerge from the data rather than being shaped by a pre-existing framework. The process involved the following steps:

1. Familiarisation with the data – All transcripts were read multiple times to ensure immersion, and initial notes were made to capture early impressions.
2. Generating initial codes – Data were systematically coded for features relevant to the development of *Spring PGD*, using an open-coding approach.
3. Searching for themes – Codes were examined for patterns, and potential themes were identified based on their prevalence and significance.
4. Reviewing themes – Themes were refined by checking coherence within themes and distinctiveness between themes, ensuring they accurately represented the dataset.
5. Defining and naming themes – Each theme was clearly defined, and thematic maps were developed to illustrate relationships between themes.
6. Writing the report – Themes were supported with illustrative data extracts to ensure transparency and credibility.

To enhance the reliability of coding, 10% of the data were independently double coded by an undergraduate psychology student. Discrepancies were discussed and resolved through consensus. To ensure rigour and reflexivity in the analysis, emerging themes were regularly discussed within the research team. These discussions provided an opportunity to challenge assumptions, explore alternative interpretations, and refine the definition of themes. Through this iterative process, we sought to enhance the credibility of our findings by incorporating multiple perspectives and ensuring the themes remained grounded in the data. Additionally, these discussions helped to identify potential researcher biases and maintain analytical transparency.

2.8. Using qualitative findings to guide intervention development and refinement

The qualitative findings were used to guide the development of a preliminary outline for the intervention, alongside the existing evidence base. This outline was shared with all participants via email for their feedback, ensuring their perspectives were

incorporated into the final design. The content was reviewed to ensure it was broadly applicable to the diverse needs of individuals experiencing PGD. In addition to the feedback from primary stakeholders, a workshop was held at a national conference, and consultations were conducted with individuals from minority ethnic backgrounds to address the gap in stakeholder diversity. Practical aspects, such as user-friendly interfaces and accessibility for individuals with varying levels of digital literacy, were also considered alongside stakeholder feedback. The refined outline then informed the creation of storyboards, the design of the digital programme, and its planned delivery. The *Spring PGD* web-app was then developed by a digital design agency based in the UK.

3. Results

3.1. Participants

Participants with lived experience of PGD were seven females and three males with a mean age of 48 (SD = 14.2), who were bereaved in different ways. Participants had lost loved ones to suicide, homicide and natural causes. Two participants lost loved ones during the COVID-19 pandemic. All participants described their ethnicity as White Welsh or British. All but two of the participants had previously received counselling or psychological therapy for grief related mental health problems. Participant characteristics are shown in Table 1.

Participants with relevant professional experience were six females and six males. All but two had clinical roles that involved the provision of counselling or psychological support to bereaved individuals. Two had prior experience of delivering a digital intervention. Participant characteristics are shown in Table 2.

In-depth, semi-structured interviews were conducted via Zoom, with each interview lasting between 22 and 59 minutes.

3.2. Qualitative results

The qualitative data collected aimed to guide the development of the digital intervention. From the interviews, several overarching themes emerged related to the development of the intervention, including: (1) acceptability of a digital approach; (2) challenges in adjusting to loss and finding meaning in life; (3) the importance of timing; (4) the need for simplicity in the delivery of therapy; and (5) optimal content delivery for user engagement.

Table 2. Characteristics of participants with professional experience of prolonged grief.

	Pseudonym	Gender	Ethnicity	Clinical role	Previous experience of delivering digital intervention
1	Rob	Male	White British	Yes	Yes
2	Amanda	Female	White British	Yes	Yes
3	Chris	Male	White British	No	No
4	Nicola	Female	White British	Yes	Yes
5	Peter	Male	White British	Yes	No
6	James	Male	White British	Yes	No
7	Laura	Female	White British	No	No
8	Julian	Male	White British	No	No
9	Sue	Female	White British	Yes	No
10	Lucy	Female	White British	Yes	No
11	Helen	Female	White British	Yes	No
12	Paul	Male	White British	Yes	No

3.2.1. Acceptability of a digital approach

A theme emerged regarding the acceptability of a digital approach to PGD treatment, consisting of three sub-themes: (1) a perceived lack of bereavement support; (2) positive attitudes towards digital intervention; and (3) concerns over accessibility.

(1) **Perceived Lack of Bereavement Support**
Participants commonly felt that existing treatment options for PGD were insufficient, with many reporting limited or unhelpful support from General Practitioners (GPs). Rebecca shared: 'Doctors were not very helpful … they said, "you know more about it than me anyway."' Others, like Anne, struggled to access timely support, noting: 'There's just nothing there … if I could have spoken to someone, it would have made a huge difference.'

(2) **Positive Attitudes Towards Digital Intervention**
All participants showed enthusiasm for a digital approach, particularly considering the limited existing support. Amy, with both lived and

Table 1. Characteristics of participants with lived experience of prolonged grief.

Pseudonym	Age	Gender	Ethnicity	Cause of death	Relationship to the deceased	Previously received grief counselling /therapy	Bereaved during the COVID-19 pandemic
Amy	40–49	Female	White British	Suicide	Husband	Yes	No
Gillian	50–51	Female	White British	Suicide	Son	Yes	No
Rebecca	30–39	Female	White British	Natural	Sister	Yes	No
Sian	50–56	Female	White British	Natural	Mother	Yes	No
Ellen	30–39	Female	White British	Homicide	Brother	Yes	No
Anne	50–59	Female	White British	Natural	Mother	Yes	No
Linda	60–69	Female	White British	Natural	Mother	No	No
Robert	20–29	Male	White British	Natural	Father	No	Yes
Philip	60–69	Male	White British	Natural	Wife	Yes	Yes
Ben	30–39	Male	White British	Natural	Mother	Yes	No

professional experience, stated: 'It's an amazing thing … many people would benefit from this.' The convenience of receiving therapy from home was a key advantage highlighted by participants.

(3) **Concerns Over Accessibility**
While digital solutions were generally well-received, concerns about accessibility arose, particularly for older individuals or those in deprived areas. Amy pointed out: 'Not everybody has access to technology … and some may not be comfortable using it.' Paul echoed this concern, highlighting digital exclusion, especially among older adults, who are more likely to experience PGD.

3.2.2. Challenges in adjusting to loss and finding meaning in life

Several factors were found to hinder individuals' ability to adjust to loss, including (1) reluctance to let go of grief; (2) avoidance; (3) unhelpful thoughts; (4) difficulties accepting the loss; (5) trauma; (6) challenges recalling happy memories; and (7) harmful coping strategies.

(1) **Reluctance to Let Go of Grief**
Many participants expressed a reluctance to 'move on' with their lives, viewing it as a sign of disloyalty to their deceased loved one. Some felt that holding on to grief allowed them to maintain an ongoing connection with the person they had lost. Professionals suggested that prolonged grief could demonstrate continued loyalty to the deceased and serve as a signal of mourning to others. Nicola noted that, for some, experiencing prolonged grief served a purpose: 'Having that grief and denying themselves pleasure or being depressed served a purpose for them. It demonstrated to themselves and the world that they still miss the person they've lost.' These sentiments were shared by many participants with lived experience, who emphasised the importance of maintaining a connection with the deceased and cautioned against the notion of 'moving on.' They felt that terms like 'recovery' or 'leaving it behind' implied severing ties with the memory of their loved one, a notion they felt uncomfortable with.

(2) **Avoidance**
Avoidance was frequently cited as a barrier to processing grief. Participants described distracting themselves through work or avoiding reminders of the deceased. Ben shared, 'I threw myself into a big work project and I could have completely avoided that. The stress got on top of me, but I only really started reflecting last year during lockdown.' Ellen explained that digital interventions could help individuals face and overcome avoidance: 'With somebody's support, I can go out and do that thing that is terrifying to me … and really feeling like I've actually achieved that.'

(3) **Unhelpful Thoughts**
Participants often struggled with feelings of guilt, blame, and anger, hindering their adjustment to loss. Linda expressed guilt over not noticing her mother's declining health sooner: 'The guilt that I carry … will stay with me forever … I carry a huge burden of responsibility for her dying.' Robert's anger towards the care home system led him to avoid confronting his grief: 'I don't know whether it's really anger or frustration, but you just think he should have been safe where he was.'

(4) **Difficulties Accepting the Loss**
Accepting the loss was a major challenge for many. Mike found it difficult to accept his wife's death: 'I had a very difficult time accepting it … I found it extremely difficult to accept what had happened.' Linda felt the COVID-19 pandemic delayed her ability to grieve properly: 'I feel the pandemic put everything on hold … I just feel as though she's going to walk through the door.' Clinicians like Julian emphasised that inability to accept the loss can block the grieving process: 'They can't accept that their loved one has just died, it's inevitable … that anger, it's a block to bereavement.'

(5) **Trauma**
Trauma often complicated the grieving process. Participants such as Gillian and Rebecca shared how trauma-focused therapy helped them manage painful memories, allowing them to better focus on their grief. Gillian explained: 'Once I could deal with the PTSD, it helped me move on dramatically. But I then had to focus on my grief.' Rebecca also reflected: 'I could deal with the trauma and move on … it was like a weight lifted, but I still had to focus on the grief after.'

(6) **Difficulties Recalling Happy Memories**
Many participants struggled to recall positive memories of their loved ones, with negative or traumatic memories dominating their thoughts. Gillian shared: 'Every time I thought of him, all that kept coming up was the times I'd been cross with him … when I shouted at him or made him cry.' Linda explained how traumatic memories blocked positive memories: 'I can't relive those happy memories with her at the moment … I only remember the traumatic stuff.'

(7) **Harmful Coping Strategies**
Harmful coping strategies, like alcohol use and self-neglect, were common. Ben shared:

'I started doing everything wrong … I was drinking heavily, I was self-harming … I kept thinking she would come home.' Amy emphasised the importance of self-care in recovery: 'Self-care is a huge part of it … it's not about being selfish, it's about recognising yourself again and putting everything into perspective.' Sue pointed out that some individuals hold on to their loved one's belongings as a coping strategy: 'In prolonged grief, you might hear stories about people not being able to clear away property or belongings … that inability to deal with the practical impact of it.'

(8) **The Importance of Timing**
A theme emerged around the importance of timing, with two key sub-themes: (1) a desire for timely support; and (2) the significance of anniversaries.

(9) **A Desire for Timely Support**
Participants highlighted frustration with the lack of timely support. Anne described her struggle to access help. She joined a lengthy waiting list for counselling through a bereavement charity, but her mental health deteriorated to the point where she was referred to a crisis team. She reflected on how the lack of support had a significant impact on her well-being: 'It kind of hits you and there's just nothing there and I think if I could have spoken to someone about it rather than just carried on with life and thinking everything's okay when it truly isn't … it's just caused a huge mental health problem for me because I wanted to commit suicide pretty much every couple of weeks, overdosing.' At the time of the interview, Anne was receiving treatment from a Community Mental Health Team (CMHT) and counselling from a bereavement charity, but her struggles were ongoing: 'Even this Monday I was prepared to take an overdose because I'm just struggling to live without my mum and not understanding why she's not here.' In another extreme case, a participant accessed support 32 years after first perceiving a need.

(10) **The Significance of Anniversaries**
Anniversaries were identified as significant yet challenging points in grief. Amy noted, 'You live by a clock and calendar … marking anniversaries in your own way helps families cope.' She also highlighted that grief doesn't end with the first anniversary, with later ones being just as painful: 'The second anniversary can be just as hard as the first, especially after a sudden death.' Participants also felt pressure to mark these dates meaningfully. Ellen reflected, 'Some families want to mark the day but need guidance on how to make it special … and permission to do nothing if that's what feels right.' Rob added that rituals, especially for the loss of a child, can be helpful: 'For some, having a ritual is important, but it shouldn't be prescriptive.' Nicola emphasised that the programme should offer ongoing support around anniversaries: 'Support is crucial when people hit milestones like anniversaries.'

3.2.3. Optimal content delivery for user engagement

A key theme identified was the need for simplicity and a focus on user engagement in delivering information, broken down into four sub-themes: (1) interactivity; (2) minimal text; (3) video content; and (4) a calm, uncluttered visual appearance.

(1) **Interactivity**
Participants highlighted the importance of interactivity to maintain engagement with the programme over time. Rebecca suggested incorporating interactive features like 'click something or do something to keep that engagement there, so you feel like you're fully engaged in it.' Ellen expressed a preference for receiving feedback on interactive tasks, saying, 'I like the idea that I get something back, you know if I give something to the app, the website, or whatever, I get something back and like a 'you got that correct'.'

(2) **Minimal Text**
Most participants agreed that the volume of text should be kept minimal, with a preference for alternative formats like audio or video. Audio was particularly favoured for its flexibility, allowing users to engage while doing other activities. Some professionals noted that text-based information might be challenging for people with PGD and that this may impact engagement, suggesting the use of clear visuals alongside concise text. However, some participants, particularly those who preferred reading, wanted options for text-based content as well.

(3) **Video Content**
There was strong support for using video content to convey experiences, with participants suggesting that real-life or acted testimonies could help users feel less isolated. However, some cautioned that such content could be triggering for certain individuals, highlighting the need for a balance. Representing diverse types of bereavement, such as sudden death, suicide, and the loss of a long-term partner, was also considered important. However, professionals advised against focusing too narrowly on specific experiences, suggesting a more general approach to ensure broad relevance.

(4) **Visual Appearance**
Participants expressed a preference for a simple,

calm design. Soft, natural colours were recommended to avoid overwhelming users, with many advocating for a professional, easy-to-navigate interface. Some professional stakeholders stressed the importance of ensuring the design was gender-neutral and culturally diverse, avoiding stereotypical or overly religious imagery.

3.3. Intervention

Spring PGD is an eight-week guided digital therapy developed based on insights from stakeholder interviews and lessons learned from the development of *Spring PTSD*, including strategies to enhance user engagement and adherence such as interactive content, regular therapist check-ins between sessions, user-friendly navigation. It is designed for people with a clinical diagnosis of PGD. The digital programme comprises audio-narrated content delivered in eight steps, featuring interactive elements allowing user input and control. The programme includes four characters with PGD following various bereavement experiences, portrayed by actors. A toolkit offers easy access to key programme components.

Therapist guidance involves a one-hour meeting to establish rapport, provide log-in details, and demonstrate the programme. Subsequent fortnightly meetings, lasting 30 minutes, can be conducted face-to-face or remotely, based on user and therapist preference. To support sustained engagement and reduce dropout, the programme incorporates four brief therapist contacts between sessions. These brief check-ins provide encouragement, address emerging issues, and help users set and achieve goals throughout the intervention.

Spring PGD is designed for use on various devices, including PCs, laptops, tablets, and smart phones. Therapists can monitor patient progress via a clinician dashboard.

Tables 3 and 4 outline the key components and functionality of Spring PGD, highlighting how these features were shaped by the co-production process.

Table 3. Overview of *Spring PGD* components influenced by the co-production process.

Step	What participants said	How this shaped *Spring PGD*
Step 1: Understanding PGD	Participants expressed frustration with the lack of adequate bereavement support in the UK, often feeling isolated and unable to access timely care. Some reported experiencing severe distress due to delays in therapy, highlighting the need for accessible support. Participants with lived experience of PGD struggled with the idea of 'moving on' and wanted to maintain a connection with their loved one.	Step 1 introduces relatable case studies of four individuals sharing their grief experiences, helping combat isolation and providing an accessible entry point. It also offers psychoeducation on PGD and the rationale behind Spring PGD, which is centred around living a meaningful life while honouring the deceased, rather than 'moving on'.
Step 2: Looking After Yourself	Many participants struggled with self-care and often resorted to harmful coping strategies such as alcohol consumption, self-neglect, or cognitive avoidance.	Step 2 focuses on self-care as a foundational component of therapy, providing practical tools such as mindfulness, relaxation techniques, and grounding strategies. This step ensures participants develop healthy and sustainable coping mechanisms to manage distress.
Step 3: The Story of Your Loss	Many participants struggled with accepting their loss, often avoiding memories or reminders, which hindered emotional processing. Feelings of guilt, anger, and blame were common.	Step 3 incorporates imaginal exposure, guiding participants to write about their loss in the first-person present tense and then re-read and update their story with any new information or memories. The story becomes part of their personal toolkit, which they are encouraged to read aloud daily if it causes distress, for at least half an hour or longer until it becomes easier. Participants receive written instructions and a guidance session with a therapist focused on this task, with ongoing support to manage distress and encourage engagement.
Step 4: Remembering the Person You Lost	Participants wanted to maintain a connection with their loved one, but thinking about them often triggered pain rather than happy memories. In some cases, this led to avoidance.	Step 4 helps participants explore meaningful ways to honour their loved one while continuing to live a fulfilling life. The programme uses techniques such as active grieving (e.g. listening to their loved one's favourite song or visiting a meaningful place) to help reprocess painful memories. Activities like creating a memory jar or personalised rituals allow participants to sustain their bond with the deceased in a way that shifts the focus from pain to more positive and constructive remembrance.
Step 5: Re-engaging with Life	Many participants struggled to engage in pleasurable activities or social interactions, feeling disconnected from the world around them.	Step 5 supports participants in identifying their core values and setting small, achievable goals to reintroduce meaningful activities into their lives. It encourages gradual re-engagement in work, social interactions, and hobbies.
Step 6: Thoughts and Feelings	Participants reported feeling stuck in negative thought patterns, including guilt, self-blame, and anger, which prevented them from moving forward.	Step 6 integrates cognitive techniques to help participants challenge and reframe unhelpful thoughts.
Step 7: Honouring the Loss	Many participants struggled with how to remember their loved one in a meaningful way that felt right for them. Traditional remembrance practices did not always feel appropriate or helpful.	Step 7 provides a flexible approach, allowing participants to find personal ways to honour their loved one.
Step 8: The Future	Participants expressed anxiety about managing their grief long-term, particularly during anniversaries or significant life events.	Step 8 consolidates the skills learned throughout the programme and provides strategies for maintaining progress over time.

Table 4. Overview of spring PGD functionality influenced by the co-production process.

Feature	What participants said	How this shaped *Spring PGD*
Interactive Content	Participants expressed a preference for engaging and interactive features to maintain motivation and attention.	The programme includes interactive tasks, audio narration, and video content to keep users engaged. These features align with participant preference for interactivity and offer a more engaging experience, ensuring users stay motivated and engaged with the content.
Therapist Guidance	Participants highlighted the importance of consistent support and follow-ups throughout therapy.	The programme includes an introductory session, bi-weekly follow-ups, and brief check-ins between sessions. This structure ensures that participants receive ongoing encouragement and guidance, addressing the need for regular support throughout the therapy.
Support for Family and Friends	Family support was identified as crucial for the grieving process, with participants expressing a need for guidance on how to help their loved ones.	The programme provides information for family and friends on how to understand PGD and best support their grieving loved ones. This inclusion acknowledges the vital role of family support and ensures that the support network is well-informed and equipped to assist the participant during their grief journey.

4. Discussion

Spring PGD is a guided digital therapy designed for individuals with PGD. Based on CBT with a grief specific focus, the intervention is built on evidence-based therapeutic techniques while being shaped by insights from both those with lived experience of prolonged grief and professionals with relevant knowledge and expertise. Qualitative data, capturing participant experiences, preferences, and challenges, informed its development. These insights influenced the content, presentation, and delivery of the programme, ensuring it is user-friendly and responsive to the specific needs of individuals with PGD.

4.1. Addressing the need for accessible and effective support

One of the key themes identified in the qualitative interviews was the perceived lack of adequate bereavement support in the UK. Many participants expressed frustration with the limited or unhelpful support available from healthcare professionals. Delays in accessing therapy often exacerbated their distress, in some cases leading to escalating mental health difficulties and the need for crisis intervention or even suicide attempts. In response, *Spring PGD* was developed to bridge the gap by providing an accessible guided digital solution that can help overcome many of the barriers to timely support. The guided digital format was unanimously endorsed by participants, who highlighted the convenience of engaging with therapy from home. However, concerns regarding digital accessibility also emerged, particularly in relation to older adults or those in deprived areas. This feedback highlights the importance of considering technological barriers when designing and implementing digital interventions to ensure equitable access.

4.2. Living a meaningful life while continuing to honour the person lost

Participants emphasised the importance of maintaining a connection with the deceased, expressing a desire to avoid the notion of 'moving on,' which they felt would diminish the significance of their relationship. They cautioned against terms like 'recovery' or 'leaving it behind,' as these implied severing ties with the memory of their loved one. In response, *Spring PGD* is framed around the concept of living a meaningful life while continuing to honour the person they lost, rather than moving on from them. This central aim is integral to the therapy. The programme helps participants develop healthy coping strategies, reprocess their grief, and challenge unhelpful thinking patterns. A key part of this process involves guiding individuals to recognise less helpful ways of honouring their loved one and explore more meaningful alternatives, such as creating a memory jar or a memorial, which allow them to preserve their connection in a healthy, constructive way.

4.3. The role of self-care and healthy coping strategies

Many participants had resorted to harmful coping behaviours, such as alcohol consumption, self-neglect, or cognitive avoidance, to cope with the intense emotions associated with their loss. This highlighted the need for a therapeutic approach that not only addresses the grief itself but also equips individuals with the tools to adopt self-care practices and healthier coping mechanisms. *Spring PGD* responds to this need by incorporating self-care as a foundational component of therapy, ensuring that individuals are provided with practical, accessible tools to navigate their grief. Participants consistently emphasised that learning to care for themselves had been a vital part of their ability to manage their grief, reinforcing the importance of this focus within the intervention.

4.4. Supporting memory re-processing and reframing

A key theme that emerged from the qualitative findings was the difficulty participants faced in

accepting their loss, with many struggling with feelings of guilt, anger, and blame. For some, memories of the loss were traumatic, leading to avoidance of memories and reminders, preventing them from processing their grief. To address this, *Spring PGD* incorporates imaginal exposure, an evidence-based technique that guides participants to write about their loss in the first-person present tense and to repeatedly re-read these accounts, if necessary, to gradually reprocess their memories of losing a loved one. *Spring PGD* also introduces the concept of active grieving, which involves engaging in activities that act as reminders of the deceased, such as listening to their favourite song, or visiting a place they loved. Additionally, the programme includes components that encourage participants to actively remember and focus on the happy times they shared. This approach helps individuals overcome avoidance, process negative or traumatic memories, and move beyond solely focusing on the pain of loss. Furthermore, cognitive techniques are introduced to help participants challenge and reframe unhelpful thoughts that hinder their ability to move forward in the grieving process. By offering these tools, the programme provides a practical framework to support individuals in processing and managing their grief in a healthier and more constructive way.

4.5. Programme features and engagement

Engagement and adherence are recognised challenges in digital mental health interventions, often influenced by users' motivation, digital confidence, and competing life demands. Stakeholders in this study highlighted these barriers and contributed suggestions to improve sustained use. To ensure high levels of engagement with the programme, several interactive features were incorporated based on participant input. These include audio narration, interactive tasks, and video content, all of which support a dynamic and engaging user experience. Participants expressed a preference for minimal text and visual elements that are easy to navigate, which led to the development of a simple, calming design with clear visuals. The inclusion of video case studies, featuring characters with diverse grief experiences, further enhances engagement by providing relatable examples of how others navigate the process of grief. These case studies not only serve as educational tools but also help to combat the isolation that many people with PGD experience.

Building on stakeholder feedback and lessons from Spring PTSD, the programme is designed as a fully guided intervention. It incorporates regular brief therapist check-ins between sessions, which aim to maintain motivation, provide support, and reduce dropout risk. These check-ins complement the interactive content and accessible design to promote sustained engagement throughout the eight-week therapy.

4.6. Strengths and limitations

A key strength of this work was the systematic co-production approach. The development of *Spring PGD* was informed by rapid literature reviews, which provided an evidence base that was then presented to participants in advance of qualitative interviews. This approach ensured that the intervention was shaped by a combination of lived experience, professional expertise, and existing research, strengthening its relevance and applicability. Our recruitment strategies helped ensure that intervention development was informed by a broad spectrum of experiences and knowledge.

However, several limitations must be acknowledged. The qualitative interviews were conducted online, meaning individuals without internet access were not included. While this may be appropriate given the digital nature of the intervention, it would have been valuable to gather perspectives from those with limited digital access to better understand potential barriers to engagement. Similarly, delivering digital therapy online poses challenges, particularly for users who may experience digital exclusion or find technology difficult to navigate. To mitigate these issues, it is essential to incorporate robust support mechanisms, such as regular therapist contact and user-friendly design, to promote engagement and accessibility. Future research and evaluations will need to explore these factors in greater depth to ensure the intervention is equitable and effective across different user groups.

The sample size for the study was small, but this is formative co-production work and a preliminary step with future larger-scale studies planned to capture a broader range of experiences. Another limitation relates to participant diversity. All interview participants were white, which may limit the applicability of findings to individuals from other ethnic backgrounds. However, efforts were made to enhance inclusivity, including consultation with individuals from ethnic minority backgrounds on key aspects of the programme, such as imagery and character representation (e.g. the inclusion of a Muslim character). Additionally, we have established partnerships with organisations that will support targeted recruitment in the next stage of evaluation to ensure greater diversity. Regarding data analysis, a single researcher conducted the primary analysis, which may introduce potential bias. However, to enhance rigour, 10% of transcripts were double coded by a second researcher, and findings were subject to continuous discussion within the research team. Finally, while the co-

production approach allowed for valuable input from stakeholders to shape the intervention, not all participant suggestions could be implemented. For instance, although some participants expressed a desire for access to support earlier in the bereavement process, the intervention is specifically designed for individuals meeting diagnostic criteria for PGD, reflecting the need to allow space for natural grieving before introducing a targeted clinical intervention.

4.7. Future research

The evaluation of *Spring PGD* will follow a phased approach, with a feasibility RCT progressing to a definitive trial if indicated. This will be guided by the MRC framework for developing and evaluating complex interventions, ensuring a systematic and evidence-informed approach (Skivington et al., 2021). The feasibility RCT will assess key factors such as recruitment, retention, and acceptability, providing important data on the practicality of delivering the intervention and its preliminary effects. Particular attention will be paid to engagement, recognising the unique challenges associated with digital therapy, such as maintaining user motivation, minimising drop-out, and ensuring participants feel adequately supported with minimal face-to-face interaction. We will also work with relevant organisations to ensure a more diverse sample of participants. If feasibility outcomes indicate that further evaluation is warranted, a full-scale RCT will be conducted to examine the clinical and cost-effectiveness of *Spring PGD*. This staged approach will ensure the intervention undergoes rigorous evaluation and contributes to the evidence base on digital interventions for grief-related mental health problems.

If *Spring PGD* proves to be effective, it has the potential to be translated and culturally adapted for use in other countries, as we have done with *Spring PTSD* (Gelezelyte et al., 2024). This would involve modifying content, language, and delivery methods to ensure the intervention is culturally relevant and suitable for different healthcare contexts. Additionally, there may be scope to adapt *Spring PGD* for other forms of loss, such as those affected by pregnancy or neonatal loss, or struggling to adjust to the breakdown of a relationship. To maximise the impact of *Spring PGD*, future research could explore its integration into existing bereavement services and examine whether modifications to the guidance (such as different levels of support or guidance by less experienced therapists or peer supporters) impacts cost-effectiveness and engagement.

If *Spring PGD* shows promise, it would represent a significant advance in the treatment of PGD in the UK. The scalable nature of guided digital therapy offers the potential to reach a broader population than traditional face-to-face therapy, particularly in regions where access to specialised mental health services is limited. This is crucial given the substantial and growing demand for mental health support following bereavement, which has been exacerbated by recent global events such as the COVID-19 pandemic, the escalating impacts of climate change, and ongoing violence and conflict, all of which have resulted in widespread loss of life (Ojala et al., 2021; Tang & Xiang, 2021).

4.8. Clinical implications

Guided digital therapies, like *Spring PGD*, offer significant advantages, such as reduced costs and flexibility, enabling more people to access timely support and overcoming the lengthy waiting times often associated with mental health services. This is particularly relevant in the context of the UK's NHS, where mental health services are under considerable strain. Furthermore, *Spring PGD* aligns with the growing focus on patient-centred care in mental health treatment. *Spring PGD* represents an important step toward expanding access to evidence-based support for those with PGD. This is especially important as many individuals face barriers to traditional psychological therapies, such as cost, limited therapist availability, and stigma. The flexibility of *Spring PGD* also allows users to engage at their own pace, which may be particularly beneficial for those experiencing fluctuating motivation during prolonged grief.

Once evaluated, *Spring PGD* could be integrated into stepped-care models as a lower-intensity intervention before progressing to more resource-intensive therapies. Future implementation efforts should explore how it can be embedded within healthcare pathways, such as primary care and bereavement services. Collaboration with clinicians and support organisations will be key to ensuring appropriate referral pathways and identifying situations where *Spring PGD* is most beneficial. If proven effective, *Spring PGD* could help alleviate the burden of PGD on both individuals and healthcare systems, contributing to more accessible and equitable bereavement care.

Author contributions

CL, JIB, NK and NR conceived and designed the study. CL collected the data and all authors were involved in analysing and interpreting the data to inform the intervention. All authors contributed to the manuscript. The corresponding author confirms that all listed authors meet the criteria for authorship and that no eligible authors have been omitted.

Disclosure statement

Spring PGD was developed by and is owned by Cardiff University and, if commercialised, Cardiff

University would benefit, as would authors CL, MS, NK, NR and JIB.

Ethics approval and consent to participate

Ethics and regulatory approvals were secured from the Wales Research Ethics Committee 2 (IRAS ID: 287681). All participants provided informed consent.

Data availability statement

Data will be available upon reasonable request from the corresponding author.

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