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Engaging young carers in public health research through online lyric writing workshops during the COVID-19 pandemic

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ABSTRACT

Understanding and effectively communicating population health research findings require engagement with the lived experiences of study participants, particularly when working with under-represented groups like young carers. This challenge was amplified during the COVID-19 lockdowns. To address this, we undertook a feasibility study, involving 46 young carers across 24 online creative lyric-writing workshops. Our approach combined narrative storytelling with rhythm and poetry (RAP) to co-produce creative outputs such as lyrics, aiming to engage participants with health and wellbeing research findings. Observations and interviews collected using bricolage methodology were used to capture professional and participant perspectives. The data were analysed using grounded theory. Our finding revealed that co-production and lyric-writing served as effective tools in communicating epidemiological data. We identified four key enablers in this process: connectedness, accomplishment, self-expression and societal engagement. This study underscores the potential of skills-based lyric-writing in enhancing science communication and public engagement with under-represented groups.

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Introduction

Young carers in Wales and engagement with a national cohort study

In the local context of Wales, HealthWise Wales, an online national cohort study with over 40,000 individuals (≥ 16 years old) who live or access healthcare in Wales (Hurt et al., 2019), aims 'to facilitate public involvement and engagement in research on key health and social care issues', with a view to influencing the implementation of innovative outreach activities (Hurt et al., 2019; Townson, 2017). Through the collation of anonymized information on individual health behaviours and opinions, the HealthWise Wales platform can be used to identify groups who are at risk of poorer outcomes and to test alternative ways to engage with under-researched and hard-to-reach groups, such as informal carers (Joseph et al., 2020).

Informal caregiving has become an integral part of many societies, however there is increasing concern about the wellbeing of carers and how they manage their care-related responsibilities in conjunction with their own physical and mental health (Hirst, 2005). Carers have been shown to experience poor health, both in terms of their mental health and

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mortality risk (Hirst, 2005; Tseliou, Heslop, et al., 2019). This could be linked to the de-prioritization of self-care whilst caring for others, with carers being more likely to report unhealthy lifestyle behaviours (Tseliou, Atkinson, et al., 2019), which may negatively impact routine activities compared to their peers. Young carers are particularly at risk of experiencing mental health problems (Tseliou et al., 2018), but tend to be overlooked because most carers are of older age (O'Reilly et al., 2008), despite experiencing a more complex burden due to disruptions in their education and evolving social networks (Dearden & Becker, 2004).

COVID-19 lockdowns contributed to significant disruptions in day-to-day activities and everyday social interactions. The rules of imposed isolation can be stressful and may have a negative long-term effect on an individual's health and wellbeing (Amsalem et al., 2021; Carers Trust Wales, 2020; Landi et al., 2022). It is important that age and culturally relevant activities are available to encourage carers to take time out for themselves, through creative peer-group activities that may provide suitable opportunities for support, self-care and respite (Pienaar & Reynolds, 2015).

Rationale for this study

In this study, a pilot protocol was developed with the aim of exploring the feasibility of an arts-based engagement activity to reach out to young carers and communicate epidemiological findings. This methodology was selected based on previous findings from four focus groups, which took place in 2019 and involved 56 HealthWise Wales members selected from four economically deprived areas across Wales and representative demographic groups conducted by an independent research group (Opinion Research Services, 2019). The aim of the focus groups was to understand how to better engage underserved communities and young people with the health research supported by HealthWise Wales. During discussions on barriers and facilitators to the engagement of under-represented groups, HealthWise Wales cohort members aged 16 to 55+ years suggested that arts-based methods may be appropriate for engaging young people to communicate important messages. Suggestions from one of these focus groups ($N = 15$ participants) included a range of communication activities such as poster-making, 'storytelling', making videos, music and other animations, indicating that more creative ways to engage with younger people could be implemented through local groups because it would be a 'better fit' for the community and more likely to have a stronger influence (Opinion Research Services, 2019). We took these suggestions on board and developed a music-based public engagement activity together with a third-sector partner specializing in engaging young people through music.

Music and wellbeing

Arts-based approaches to social action can enable youth to share personal experiences of stigmatized topics which in turn can support their personal growth (McInerney, 2023). There are a range of ways that music can be therapeutic, including music listening as part of an intervention, active music engagement through playing an instrument or singing (alone or as part of a group) or music production through a combination of lyric-writing, composing and performance (Crooke & McFerran, 2019; Urbanek et al., 2021). Examples of the latter incorporate Hip Hop (a combination of poetry and music) and spoken word therapy which utilizes lyric-writing as a storytelling technique that can have a therapeutic value, especially when working with young people (Levy, 2012; Urbanek et al., 2021). Hip Hop lies at the heart of mainstream culture among youth and adults. In Hip Hop, artists often talk about experiences and concerns of marginalized populations (Levy, 2012) and these experiences can be used to establish rapport in classrooms with marginalized pupils and address poor mental health (Adjapong & Ian Levy, 2021). Similarly, beat music improvisation is increasingly being used in music therapy, as it appeals to young people (Crooke & McFerran, 2019).

Theoretical framework

This study is grounded on key theories relevant to the use of arts-based methodologies in engaging under-represented groups with public health research findings through creative expression (Howard, 2023; Manchester & Pett, 2015). Co-production, defined as a collaborative process between researchers and participants in generating knowledge (Ostrom, 1996) was a key element to ensure that the voices of young carers would be heard and valued, fostering a sense of ownership and empowerment. It also aligned with participatory action research (PAR), which seeks to democratize the research process and involves participants as active contributors rather than passive subjects (Genat, 2009; MacKinnon, 2011; Reason & Bradbury, 2001). An arts-based research method was chosen with the aim to generate nuanced insights into the participants' experiences (Leavy, 2015). The medium of music was used as a means of communication and self-expression to overcome challenges of engaging with marginalized groups (McFerran, 2010).

Aims

This study reports on the feasibility of a creative, arts-based methodology for engaging young carers with epidemiological research findings relevant to their physical and mental health. Thus, we aimed to:

- (i) develop a skills-based lyric-writing methodology for disseminating research results and providing a forum for discussion
- (ii) determine whether the chosen music-based methodology would be appealing to young carer participants as a science communication activity and would facilitate lived experience discussions.

Materials and methods

Ministry of Life (a not-for-profit organization that provides training in music and video production to young people) were identified as collaborators on this project because of previous work that they had undertaken with academic colleagues to raise awareness of educational inequalities observed in 'cared for children'. Their existing networks involving third-sector youth services (see Table 1) enabled the participation of a diverse group of young carers who were already engaging with YMCA in an ongoing programme of creative group-based respite activities. The multidisciplinary approach that evolved through working with these partners at the development stage ensured a workable schedule and format which incorporated appropriate safeguarding within the virtual environment where the music-based activities were hosted. Subsequently, the methodology was used with a second cohort of older young carers through a collaboration with The Carers Centre. This tested the repeatability of the method and its acceptability to older participants.

Terms of engagement

In line with our key operating principles (see S1 for details on ethical and confidentiality considerations) and to encourage genuine reciprocal participation of the young carers without the semblance of tokenism (Hart, 1997; McLaughlin, 2006), it was important to involve them as equals in all stages of the activity using skills drawn from both research and youth work experiences (Wood & Hine, 2009). The incorporation of co-production principles was essential to achieving genuine reciprocal and respectful participation and high-quality interactions as a result of the participants feeling that their input is both legitimate and valued.

Table 1. Project progress outline.

Planned action	Implemented action
Initial stage aiming for face-to-face sessions with HWW young carers	
Development of project methodology	Incorporating Rhythm and Poetry (RAP) to the engagement activity
Recruiting HWW young carers	Emails sent to the HWW cohort Development of email leaflet Social media posts (including email leaflet) across different platforms at key dates
Revised stage following COVID-19 disruptions	
Introducing carer-related research findings	Development of illustration
Reaching out to 3 rd party collaborators	Developing links with YMCA Developing virtual engagement approaches Development of safeguarding guidelines in collaboration with partners Receiving participant consent to share outputs
Developing new guidelines	Receiving participant consent to share outputs
Recruiting local artists	Developing links with local artists to co-facilitate interactive sessions
Developing creative outputs	Lyrics, posters and music production Music video co-development by Graphic Designer
Receiving participant & facilitator feedback	Informal feedback sessions implemented
Expanded stage replicating methodology with a wider audience	
Reaching out to organizations and charities	Emails sent to charities Developing links with Carers Trust Wales and Swansea Carers Centre
Developing creative outputs	Development of lyrics and posters
Receiving participant & facilitator feedback	Informal feedback sessions implemented Exchange wrap-up workshop
Disseminating key findings to wider public	Social media posts Newsletter on HWW COVID-related projects Newsletter on young carers only
Follow-up sessions	Providing follow-up sessions Development meetings with YMCA Lyrics and music production YMCA Young Carer Card launch event

Activity structure

A key aim was to develop a deliverable programme of activities in a secure online environment whilst implementing effective safeguarding. The structure of sessions was developed based on our logic model (Figure 1), following a model of Theory of Change (Mayne, 2017) outlining how a desired change is expected to happen in a particular context through monitoring set inputs and outputs and evidencing the impact of a methodology. In this case, it involved allowing carers the opportunity to engage with research findings in ways that are relevant to them and capturing outputs of the engagement activity as well as gaining feedback from both participants and facilitators. A dynamic process was followed during implementation, for example, during the initial 'taster' session, participants gave feedback on desired goals for the activity so that their aspirations would be respected in forming the workshop structure. This process provided an initial basis or 'social contract' for cooperation (Desmond-Hellmann, 2012; Vayena et al., 2016).

The workshop structure centred on delivering lyric-writing skills training around the topic of young carers' health. Music in the form of rhythm and poetry (or RAP) was chosen as a means of telling stories for this project, following its introduction by Mandeep Singh (a medical student and rapper) as a powerful storytelling tool in medical settings (see more at <https://lalalarecords.co.uk/isolationinyourwords/>).

Ministry of Life facilitated the sessions with young carers to provide guidance and skills training for the co-production of music, lyrics and other creative outputs. The creative process involved participants being introduced to research findings about carers' health issues as a stimulus for informal discussions about how these findings relate to their own personal circumstances and experiences. These discussions formed the basis of idea generation and collaborative drafting, review and editing of lyrics by the young carers, with a view to organizing/re-organizing the lyrics into full songs at subsequent sessions (see Lyrics – Song 6). MoL provided tuition on the anatomy of song incorporating structures such as verse, pre-chorus and chorus. Participants provided consent for

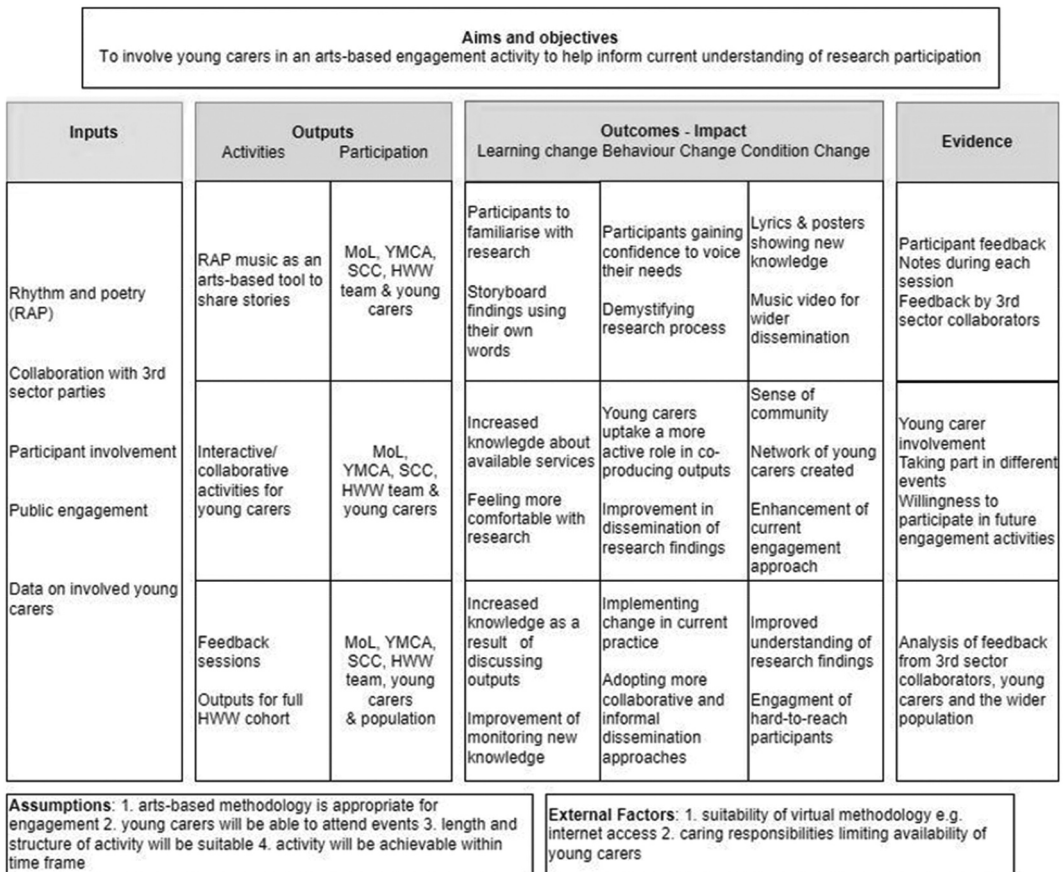


Figure 1. Logic model.

the lyrics to be used to create a music video which could be shared with the public. Although this was a music-focused activity, it was explained to the participants that they were not restricted to lyric-writing, for example, they could opt to write a paragraph or note down some thoughts which could subsequently be re-shaped into lyrics, enhancing creativity and lyrical skills. Young carers could attend one or more sessions, which lasted approximately 2 h and were implemented within our third-sector partners' pre-scheduled creative sessions, depending on their availability, interest and level of Zoom fatigue. Participants were involved with many online meetings with practitioners as a means of ensuring adequate support and access to services during the COVID-19 lockdown. However, in line with youth work principles (Davies, 2005), young people's engagement was voluntary and therefore they were given the choice of whether they would like to engage or not.

Data collection

The creative sessions were delivered in partnership with the two youth organizations who explained what the workshops involved, invited and consented young carers to take part, and acted as safeguarding officers during the sessions (see S1 Ethical and confidentiality considerations). Twenty-one sessions were delivered in cohort one (from May 2020–October 2020 and from January 2021–March 2021) and three sessions were delivered in cohort two (during October 2020). As part of our process consent ethos, verbal consent was re-obtained at the beginning of each session by Ministry of Life in the presence of the safeguarding adult (third-sector partner) to ensure that all participants

were aware of the purpose of the sessions which was to i) engage young people with health research findings, ii) identify how their own experiences relate to these findings iii) learn new skills through lessons on lyric-writing iv) co-produce creative outputs based on their lived experiences and v) jointly develop an engagement strategy where these creative outputs are disseminated to health researchers and practitioners. The data collection included observations from all sessions, three short interviews and creative outputs such as lyrics for six songs and one music video. We used bricolage, deliberately mixing data collection methods and ways of thinking (Denzin & Lincoln, 2011) to address young carers' engagement with health research data via music. An end-of-project evaluation focus group was conducted at the end of each cohort as part of a celebration event (see Table 1; follow-up sessions). These sessions were attended by stakeholders including professionals working in the youth organizations and research partners directly involved in the project. They involved reflexive dialogue on the process and discussion on co-creating the dissemination strategy, allowing a process of 'debriefing' for the young people (Harris, 1988).

Data analysis

A variety of forms of qualitative data, including observational notes from the sessions, lyrics from the young people, recordings of views from stakeholders including the young carers staff and workshop leaders, were collated and analysed. For this purpose, we developed a thematic grid drawing on a 'grounded-theory' approach (Glaser & Strauss, 1967). Similarly to Lofland and Lofland (1995), we viewed data collection and analysis as an active process by which data is produced and not simply collected; a principle which is in line with this project's co-productive approach.

In community and youth research, 'understanding voice', which refers to understanding the service user experience, is at the core of approaches shared within the social sciences (May, 2000). We used all of the collected data to create an overall picture and insight into what took place and young people's perceptions and experiences of the project. We drew together all the evidence and identified four themes that were present across interviews and fieldnotes. Inter-rater reliability was achieved through a series of meetings between the authors FT, JG and PAW where agreement on themes was reached.

Results

Uptake of project sessions and participant characteristics

Overall, 46 young carers took part in this project through 24 online engagement sessions (see Figure 2). All participants lived in two large towns in South Wales (site 1 and 2), over half were female and of White British background. The young carers expressed an interest in follow-up sessions which were subsequently arranged by the Ministry of Life and the youth organizations, increasing the reach of the project.

Following the successful implementation of the interactive sessions, the same approach was used to reach out to a second cohort of young carers. In this case, all young carers that took part were resident in a specific Welsh town (site 2), female and over the age of 21. Participants could return and take part in future sessions following their initial engagement. Participants were keen to share the outputs from the sessions and agreed to these being distributed via HealthWise Wales and Ministry of Life, as well as across their personal networks.

Engagement with research findings

HealthWise Wales data from informal carers were selected for this engagement activity. These data demonstrate important differences in the day-to-day health behaviours, mental health and well-being between carers and their peers, with carers reporting poorer mental health (Tseliou, Heslop,

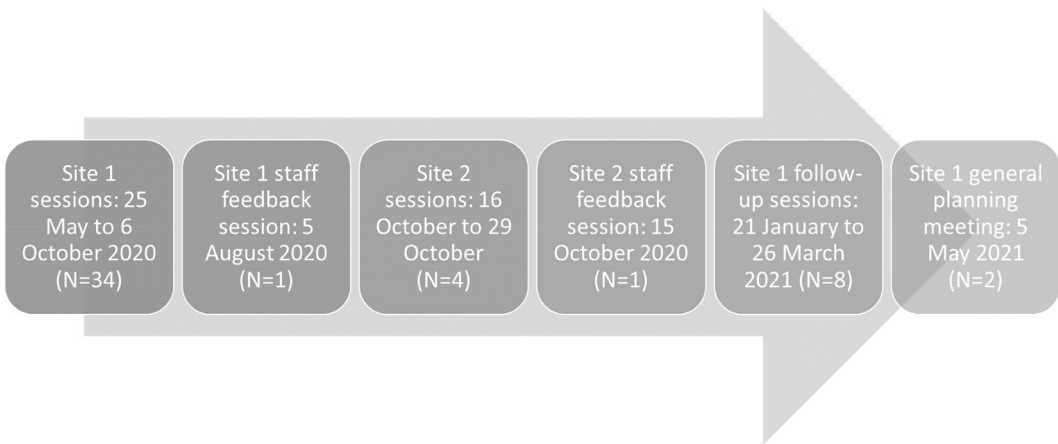


Figure 2. List of sessions delivered.

et al., 2019) and more unhealthy lifestyle behaviours than non-carers (Tseliou, Atkinson, et al., 2019). These findings were used to create infographics that were presented in an illustrated leaflet (S2. Illustration). The aim of this illustration was to evoke discourse by asking how the observed research findings might translate to the young carers' own care-related experiences.

During the workshops, the illustration was used as a basis for discussion, with facilitators listening for young carers' responses, for example, whether they agreed or disagreed with these statistics. Notably, they were not hostile to the statistics, but embraced them as an opportunity to discuss their own experiences. Young carers were given the choice to come up with lyrics that were about the illustration or about their own lives within or outside of the context of the pandemic. Participants then collectively set themselves the challenge of creating some lyrics for a song so that they would have something to be proud of by the end of the sessions.

They came up with suggestions regarding how they felt and key terms relating to their experiences as young carers while also elaborating on their reflections of the illustration. This was all conducted in an informal conversational style. As part of the lyric-writing process, the facilitator then created a mind map using the chat panel on Zoom, aiming to come up with rhyming words to create lyrics. By the end of each session, complete songs and/or several lyrics had been co-produced, with the participants having enjoyed the activity and looking forward to the next. A leaflet was also designed to provide a visual framework for the activity which was shared through social media and emailed to project partners (S3. Leaflet).

Other features of the sessions included guest appearances by local music artists who gave feedback on the young carers' creative questions and outputs. Music performances were also incorporated into the sessions honouring the ethos of reciprocal respect that was the fundamental basis for their engagement. As the implementation of the project progressed, positive comments about the sessions circulated via the participants' social networks leading to a wider awareness of the project and encouraging other young carers to join and share their perspectives.

Key themes identified in participant narratives and observations

Connectedness

Data illuminated the importance of having a source of respite for the young carers that was not previously available to them during the COVID-19 pandemic. It contributed positively to their overall wellbeing:

With COVID a lot of my groups have had to finish or there hasn't been much going on so it has been very difficult to try and be productive and carry on... in the two sessions I actually came up with something, it made me feel... like oh wait. I can do something, which is something I don't feel very often F, Site 2 session

The benefits of sharing experiences and creating links with other young people they had not met was also expressed:

it's been nice to have a chance to do something with other people, like some of them you may not know and it's nice to be able to come and sing for a little bit F, Site 2 session

Indeed, young carers spoke of the sense of companionship they shared and the role this played in being able to offload their concerns:

as a group, everyone is sharing the love together and they're all like, I have this problem and I have this problem. Then they create a bond F, Site 2 session

These examples highlight that interacting with other young carers and working together as a group during the engagement sessions played a key role in the positive experience young participants drew from the sessions.

Accomplishment

The sessions also provided participants with a sense of accomplishment that promoted their self-confidence. One participant said:

I really enjoyed them (the sessions) because it's something that I can do that's productive and it's giving me a sense of accomplishment... every time we come up with a lyric or every time I sort of actually contribute it gives me a sense of like 'hey I actually did something' which is something that I don't feel often recently, so that's helped me F, Site 2 session

Another young carer spoke of the role the sessions took in helping to build their confidence in overcoming barriers:

I was like nervous about it but like I know you are always going to be nervous and it's nice because you're not really judged and it's a sense of accomplishment as much as you think to yourself that you can't do something about it... and then having people that you don't know like a singer herself say that you can do it. It gives you like a good feeling about yourself F, Site 1 session

There were many occasions in which the young participants felt a genuine sense of achievement as a result of being a part of these workshops. It highlights the importance of co-producing outputs with young carers who are given the opportunity to gain new skills and feel a sense of achievement and pride for their contribution.

Self-expression

Having the opportunity to express their feelings and thoughts through lyric-writing appeared important for young carers who faced difficulties in having their voices heard. One participant mentioned:

It's always like we are fighting for a spot with different people and obviously is so nice to just let your feelings out and just make sure they are actually done in a productive way F, Site 2 session

Another participant spoke of the value of feeling heard through expression:

you're getting your emotions out on paper which I think has been proven as a good way to get your emotions out. Without it you can't talk to somebody, but not only that, you are having your voice heard because in a group you put your emotions down and you find out that people around have other ideas and other thoughts and it's kind of like a group therapy session F, Site 2 session

Furthermore, another young carer highlighted the importance of having an opportunity for expression that was channelled through a productive and creative environment:

It's really good because being able to get your emotions out there in a constructive way, that isn't just you off loading to other people which can be damaging to other people when their mental health is bad as well F, Site 2 session

All these examples demonstrate the role of music and lyric-writing as a form of self-expression in communicating emotions and raising awareness on issues that are important to young carers.

Societal engagement

Finally, the legacy of the activities was highlighted by young carers in terms of the potential impact that creative outputs can have on other young carers. One young carer stated that:

you do create the song at the end of the session, you got that you can put out to the world and get other people to think that hey that's relatable. It sort of has a knock-on effect afterwards F, Site 2 feedback session

Another participant went on to speak of the way in which young carers could acknowledge the lived experiences of others in a similar situation to their own:

That can guide the younger generations and again it gives them the chance to say this is a really good idea. I think this can be done in a way that is engaging with the younger people who know what it's like because they have been there F, Site 2 feedback session

Furthermore, young carers had a sense of pride as a result of their involvement with the workshops, clearly valuing being involved in the research and the positive impact this could have on others:

we are the future generations, but they're going to be future generation who are younger than us and they need to have wisdom from us who have been through that, they need to have that guidance that other people won't give them F, Site 2 feedback session

Overall, these findings highlight that participation in the engagement sessions was a positive experience for young carers by enabling opportunities for self-reflection, connectedness, promoting a sense of accomplishment, encouraging self-expression and enhancing societal engagement.

Co-producing creative outputs

During the interactive activities, a range of lyric-based outcomes were developed, depending on the needs and preferences of the participants. Young carers identified issues that were important to them while also drawing information from the illustration, with topics including differences between young carers and their peers, food and alcohol and how this relates to poor health as well as the impact of COVID-19 on their daily lives and caring responsibilities. These discussions prompted lyrics which highlighted their personal views (S4. Lyrics).

Through their lyrics, they described the following experiences and aspects of daily life which were important to them. Young carers raised some key topics (see Table 2) as they:

Table 2. Lyrical themes and samples.

Themes	Lyrics
Being a carer	<i>'You've worked so hard missed out on sleep – You've been there for others when times looked bleak' 'You should know some carers are hidden – It's a third of all people I'm not kiddin'</i>
Behaviours & wellbeing Mood & being heard	<i>'You might think you have a clue but watch out for your mood – Look out for your health be yourself' 'But when I'm down – Will you please let me stay down – I have a right to my mood' 'I may be small – But I have a voice too'</i>
Social support Expression through music	<i>'As I get home I start to feel alone' 'Music helps my thoughts process – Even when life feels a mess'</i>
COVID-19	<i>'In lockdown we can't do anything – But on the plus side I've been able to sing'</i>

- (i) described how they personally experienced their role as carers and how different aspects of their caregiving responsibilities can negatively affect their health and wellbeing, resulting in them losing sleep and their needs remaining '*hidden*'
- (ii) discussed how important it can be to focus on their wellbeing and being mindful of the impact of unhealthy behaviours such as unhealthy eating, smoking and physical inactivity, on their mood especially during the COVID-19 pandemic
- (iii) expressed their attitudes on the right to experience different moods and feelings during challenging circumstances and stand up to being underestimated or not '*having a voice*' due to their young age
- (iv) acknowledged that support from family, social relations with friends, and interacting with others can improve health and wellbeing overcoming feelings of loneliness
- (v) indicated that making music can help them acting as a creative way to cope with negative thoughts and stressful situations which stem from carer-related responsibilities
- (vi) considered the changes that have occurred in daily activities during the COVID-19 pandemic leading to carers feeling overwhelmed and how art and music can overcome boredom.

The facilitators worked closely with young carers to develop ideas for a music video 'graphic' that would draw on the themes of the song. The 'graphics' were used as the basis of the music video that was created by a Graphic Designer to accompany the song and highlight the key feelings and thoughts expressed by the young carers (S5. Music video). Furthermore, short videos in a Graphics Interchange Format (GIF) were developed (S6. Short video) using quotations from young carers regarding their experiences during the interactive sessions, and some of the lyrics were used for the dissemination of key findings to wider audiences (S7. News story; S8. Newsletter).

This creative output was further utilized beyond the implementation stage, which can be illustrated through the example of one young carer who took part in the co-production of the song and music video, during the launch event of the YMCA Young Carers' ID card scheme (June 2021). This event focused on enhancing recognition of young carers' roles and was attended by a project partner as a guest speaker. Participation in this event showcased the strength of the partnerships created during the project and expanded the impact of the project, achieving further outreach through live-streaming of the event and social media dissemination by project partners. After receiving positive feedback for their creative output, one young carer responded:

Thanks that's my song

Demonstrating that they were proud of the work that they had produced.

Carers developed a keen interest in lyric-writing as this is a skill that could be used in other aspects of their lives beyond this engagement project.

Discussion

In summary, this study tested the suitability of a music-based methodology to engage young people with research outputs and give them the opportunity to interrogate and interpret observational research findings. We found that discussions around health were made possible when in a trusted and safe setting that enabled young carers to interact with their peers, take part in lyric-writing and discuss issues that were relevant to their own mental and physical health. This experiential activity was complemented by the production of 'easy to understand' lyrics which reflected their lived experiences. Through the creative medium of rhythm and poetry (RAP), young carers engaged with research findings and had conversations that might have been hard to have in a different setting. This approach resulted in young people being receptive towards the research information which related to their experience and engaged in a discussion about how research relates to lived experience.

Through introducing sessions that presented research findings on the health of carers, we were able to initiate a starting point for discussions about coping with caring responsibilities and the importance of wellbeing during the pandemic. While we did not evaluate the impact of this project on their awareness for health and wellbeing, the participants reported valuing 'having their voices heard', which research has shown is a challenge among young carers that can negatively impact their wellbeing (Dharampal & Ani, 2020). Furthermore, young carers developed interest in lyric-writing as a means of sharing their thoughts with the services directly supporting them and their wider support networks, challenging conventional research power dynamics and contributing to translational research, and thus aligning with core principles of community-based participatory research (Wallerstein et al., 2019). The interactive sessions improved understanding of young carers' issues by instigating opportunities for dialogue during the challenging COVID-19 pandemic period, which was previously shown to result in young carers feeling isolated and having limited activities (Carers Trust Wales, 2020). We will next contextualize these findings within the broader literature of creative methodologies and public engagement with science.

Creative methods in public engagement

Creative methods have been applied to a range of settings such as working with minority groups and promoting STEM learning (Bevan et al., 2016; Guo et al., 2020) highlighting the potential in youth engagement. We found that creative music-based engagement activities helped connect people with research and created interest in research findings by making them tangible and relatable. In this context, research building around passions and existing social identities of young people can advance youth interests on important health concerns and subsequently lead to identity development through engagement.

Although recent years have seen an improvement in the involvement and engagement of key stakeholders in the conceptualization, development and implementation of research (Boaz et al., 2016; Cook et al., 2017), certain groups with recognized unmet needs are still underrepresented and their inclusion in relevant conversations remains challenging (Kaiser et al., 2017). We found that a co-productive approach supported the active involvement of young people whose circumstances make participation in peer-to-peer interactions and other age- and culture-appropriate activities difficult. As observed elsewhere, experiential learning involving arts-based skills transfers such as music skills-based activities can help promote reflection and individual meaning making (Furman & Sibthorp, 2013) and improve self-confidence, skills, the ability to articulate experiences and emotions and encourage peer group support (Mannay et al., 2022). We found that arts-based methods helped build rapport with participants and opened conversations that were important to them, thus improving the feasibility of translating research findings for under-represented groups in a challenging virtual setting.

The role of creative workshops in equalising power dynamics

This project created a hybrid space between science and art, using art in the form of music to catalyse engagement with health research. Music was offered as a fun and engaging activity to young carers who had expressed interest in attending creative workshops and developing new skills. Through art-based cooperative learning activities, a multiplicity of outcomes including skills training, aesthetic outputs (plastic or performative) and a variable range of personal learning and discovery through peer-to-peer interactions was offered. Music formed a foundation for connecting young people, researchers and youth organizations to produce a song as a creative output. This created an inverted space in respect of 'power dynamics' because young carers took the role of the experts, Ministry of Life took the role of a facilitator or agent, youth charities acted as space provider and link to the young carers, and HealthWise Wales, the academic institution, took the role of 'learner' who would be 'informed' by the young people with the lived experience

or 'expertise'. This dynamic was contrary to traditional power dynamics in research settings where researchers hold disproportionate power over research participants. Although such approaches have been used before (Alminde & Warming, 2020; Oliver, 1992), we further highlight the potential benefit of utilizing democratic and empowering approaches, especially when engaging with vulnerable groups and sensitive issues.

Young carers were proud of their involvement and contribution to helping other young people. They reported that it gave the difficulties that they had faced a sense of value and meaning. They were not only aware of their contribution to public health messaging but proud of the positive difference this could make to others. They experienced this process as part of building a legacy rather than simply being subjects of someone else's legacy, leading to outputs that are nuanced and relevant to the target beneficiaries. Previous research has supported these findings, suggesting that recognizing participant experiences and building on them could help improve understanding of social dynamics and underlying pathways between inequalities and poor outcomes (Kapilashrami et al., 2015).

The introduction of HealthWise Wales' research topics through the medium of music opened new avenues for conversation between care providers and young people (as care receivers) which might not have organically arisen through usual power interactions. This was achieved through an expressive process, which aimed to allow creativity in the production of a music output in a shared creative space, empowering them to become actively involved in science. This portfolio of engagement activities builds on existing work to develop and evaluate a model of public involvement and engagement embedded in HealthWise Wales (Townson et al., 2020).

Innovations in public health research

The benefits of arts for health and wellbeing have been widely articulated (All-Party Parliamentary Group on Arts, Health and Wellbeing, 2017; Stuckey & Nobel, 2010). Music in particular has long been used in well-being interventions with young people, involving music that is age and culturally appropriate (Daykin et al., 2018; Porter et al., 2012; Rodwin et al., 2022).

However, the use of arts-based activities as a forum for dissemination of research findings to relevant population sub-groups is novel and, as demonstrated herein, mutually rewarding. When compared to linear learning, such approaches have the advantage of creating knowledge by transforming personal experiences, thus allowing individual voices to be heard and issues shared in a way that makes them tangible to a wider audience. They have also been applied to different settings such as healthcare, further highlighting the power of storytelling as a means of validating participant experiences (Restrepo & Davis, 2003). The resultant creative outputs can thus help 'visualise' individual stories by bringing them to life, leading to a wider impact than standardized dissemination strategies.

A key feature of the project was to consider the impact of research findings on their audiences, including their understanding and acceptability of such information. This also concerns public health research which supports personal reflection, group interaction and discourse around sensitive issues. We found that wider benefits can be achieved by shifting the focus from destination to participative journey, reflecting observations from research on the impact of participation in digital storytelling on health behaviours. Although storytelling methods have been primarily used when working with young people (DiFulvio et al., 2016), they could be applied to wider population groups to further explore how they may differentially impact health and mental health outcomes. Overall, this engagement activity facilitated a duality of engagement potential involving (i) participants as creators and (ii) wider public audiences as spectators of the final lyrical productions. In terms of delivery, this skills-based approach is arguably more onerous than non-skills-based methods, but the benefits and legacy to participants, stakeholders, and wider networks suggests that further development of the method in other engagement contexts may be beneficial.

Limitations

There were caveats in this online approach of delivering the music-based activities; the need for access to a stable internet connection, either through a computer or mobile phone, could exclude some young people. This limitation could be overcome by using a mixed approach, with both online and face-to-face sessions according to the young carers' needs, though this was not possible at the time of implementation due to COVID-19 restrictions. Further work is required to determine the acceptability and effectiveness of face-to-face delivery. Finally, the choice of a music-based approach could have limited the participation of young carers to those with a pre-existing interest in music or the confidence to take part in online workshops. Workshops employing a more diverse range of arts-based methods could enhance participation in the future.

Future steps

The successful engagement of different groups of young carers with research findings demonstrated that utilizing novel and creative ways to share research outputs could broaden and deepen public engagement with public health research.

It has been highlighted that evaluation of collaborative projects needs to be undertaken using formative and summative criteria; an aspect of research that has been neglected in the relevant literature (Hargreaves, 2007). In that context, key steps towards a larger scale engagement activity could include the dissemination of creative outputs and the careful consideration of feedback from involved services and third-party collaborators, engaged participants and finally the wider public. The feedback received on the creative outputs will be used to revise and improve upon engagement activities undertaken by HWW in relation to young people and further work undertaken to determine suitability for other age categories. The use of social media and newsletter posts will continue to be combined with more structured dissemination methods such as research abstracts and presentations, as each method works on different levels when engaging with diverse groups to reach out to and inform a wider audience.

Future steps could include undertaking several small projects, using mixed-methods approaches by combining qualitative along with creative arts-based methods, allowing the voice of participants to be heard and create greater understanding of the impact and use of research findings, both within the context of the HWW study but also across different research cohorts. These projects could be further used to develop case studies by inviting young carers to tell their stories about the project and how it helped them. This methodology should also be further evaluated to quantitatively assess its impact on the health literacy of young people.

Conclusion

This feasibility study employed innovative skills-based lyric-writing workshops to actively engage young carers in health and wellbeing research, departing from traditional top-down information dissemination approaches. Through creative engagement, research was made more accessible to young carers while valuing their perspectives to shape health knowledge. Our approach demonstrates principles of knowledge exchange by elevating young people's voices in the research process, highlighting its potential to facilitate authentic and meaningful engagement and communication with small groups.

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Authors' contributions

PAW conceived the study. FT, JG & PAW contributed to the study's conceptualization of methodology. JG led the implementation of the study, in collaboration with FT and PAW. FT wrote the first draft of this paper. PAW, JG and SV contributed to clarity and interpretation and the production of subsequent drafts of the paper. All authors have approved the final version of this paper.

Data availability statement

The data that support the findings of this study are not publicly available due to privacy and ethical restrictions. All queries and requests on developed materials should be submitted to the corresponding author, Dr Foteini Tseliou, for consideration.

Ethics approval and consent to participate

HealthWise Wales received a favourable ethical review by Wales Research Ethics Committee (REC) 3 ref: 20/WA/0064, 7 April 2020. This engagement activity was carried out in accordance with relevant guidelines and regulations and consent to participate and for the workshop outputs (feedback, lyrics, songs) to be shared was obtained by the workshop facilitators at the beginning of each session.

List of abbreviations

GIF	Graphics Interchange Format
HWW	HealthWise Wales
MoL	Ministry of Life
YMCA	Young Men's Christian Association

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