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A case report of Patient and Public Involvement and Engagement activities to explore the potential of zines as an arts-based tool to target the stigma of pain..

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Abstract

There is increasing evidence that stigma negatively affects the health and quality of life of people living with persistent pain. While there is a need to tackle stigma, the few studies investigating potential interventions to date have focused on individual-level interventions. However, self-stigma is experienced alongside external stigma that manifests in both private and public spheres, including interactions with healthcare providers and policies that affect the lives of people with pain. This case reports explored the potential to use zines, an art-based medium rooted in social justice activism, as an anti-stigma tool, in the context of persistent pain. This paper describes the collaborative Patient and Public Involvement and Engagement (PPIE) process to (1) develop and deliver zine-making workshops and (2) shape future research to understand zines as a potential tool to target pain-related stigma across the multilevel health ecosystem. Collaboration with patient advisors highlighted the need for inclusivity to be at the centre of zine workshops. Then considering potential for future research, people living with pain themselves and general practitioners were identified as priority groups to evaluate the impact of zines on pain-related stigma. This case report documents and shares learning about how PPIE can provide essential insights into developing and evaluating an inclusive intervention with potential to target stigma for people with pain.

Contribution of the paper

- Zines are an art-based tool that have the potential to target pain-related stigma at multiple levels.
- PPIE is of crucial importance to develop anti-stigma interventions to ensure they are inclusive by design.
- PPIE should continue to be drawn upon in the design and delivery of future research to evaluate the impact of anti-stigma interventions such as zine workshops and libraries.

Keywords
Pain, self-stigma, stigma, arts, zine, patient and public involvement and engagement

Introduction

Experiencing prejudice or discrimination negatively influences physical and mental health, precipitating health inequalities [1]. Health policies have been developed in attempts to structure actions to tackle discrimination (Equality Act, 2010 [2]), personalise access to care (Care Act, 2014 [3]) and protect the most vulnerable (e.g. Mental Health Act, 2007 [4]).

In the UK, it is estimated that 20% of the population live with persistent pain, and many experience stigma in their close relationships, workplaces, public spaces and healthcare environments [5]. Stigma describes devaluing and discrediting responses towards individuals perceived to possess a particular characteristic that deviates from social norms [6]. *Internalised* (or self-stigma) reflects feelings of shame and embarrassment about one's condition, while

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enacted stigma describes mistreatment from others toward the stigmatized group, occurring in interpersonal interactions or as the result of structural factors [7]. In the context of persistent pain, stigma appears particularly common given the invisible and subjective nature of pain [8]. Emerging research indicates that stigma is associated with increased distress and disability among this population [9]. Importantly, data indicate that stigma may not be adequately targeted in existing pain treatment approaches. In the UK, multidisciplinary pain management programmes (PMP) based on cognitive-behavioural principles are widely used to support people living with pain to improve their quality of life in the presence of pain and associated distress [10]. In one such intervention, self-stigma only changed to a small degree and, unsurprisingly, enacted stigma did not change [9]. These findings point to the need for innovative approaches that target pain-related stigma at intrapersonal, interpersonal and structural levels.

Evidence from other contexts (e.g., HIV, mental health, older adults) suggests that, among others, expressive writing targets stigma at multiple levels [11]. As a form of expressive writing, zines' potential to target stigma have not been specifically explored, nor has it been in the context of pain stigma. Zines are "do-it-yourself" self-published booklets, made of drawings, poems, collages, etc. They have been used as a way to express less represented views and experiences in an unfiltered personal publication, and often shared with others through zine libraries. Zines have a long history as a social justice action tool, from feminism to anti-racism [12], although they have also been used in other contexts, such as the politics of polish far right movement for example [13]. Such open access and unfiltered publication require for the readers to be aware that the experiences and world views shared via a zine only represent the ones of the maker. However, through the creation of an alternative media conveying the reality of marginalized and vulnerable communities, they commonly aim to connect and empower the ones who may experience stigma from the dominant culture, advocating for social change [14, 15]. Despite the social media era, the proliferation of zine libraries reflect their return to popular culture (Glasgow zine library [16]; Wellcome Collection zine library [17]; Mental Health zine library [18]).

Finally, Patient and Public Involvement and Engagement (PPIE) has become highly valued to shape healthcare planning, policies, service development, and research [19]. Creating opportunities for research to be carried out '*with'* or '*by'* members of the public, rather than '*to*', '*about'* or '*for'* them, have provided significant benefits, including designing more relevant research to respond to the population's needs and better translation of research into practice [20]. In research related to stigma, enabling the people exposed to such adversity to take part in anti-stigma intervention design can be considered an intervention in itself [11; 21]. Therefore, it is essential to involve people living with pain in the process of exploring zines as an anti-stigma tool.

Considering the above, this case report aims to share learning about how PPIE was undertaken to:

1) develop an innovative intervention with the potential to target stigma that consists of pain-related zine-making workshops and the display of a zine library
2) inform future research to evaluate zines as a potential tool to target pain-related stigma.

Case Report

Publication of PPIE is not common at present and most journals do not currently have article formats that adequately capture the nature of this type of work. Nonetheless, this is an evolving area and there are several notable examples that demonstrate the value of publishing PPIE work. For example, *Research Involvement and Engagement* is a journal that is specifically dedicated to sharing knowledge and learning from PPIE work [e.g. 22]. Adding to these examples, this paper focuses on the description of PPIE activities undertaken to develop zine workshops and to inform the design of future research on zines for people with chronic pain. This project does not meet the research definition established by the Health Research Authority (HRA) [23] as it was not designed to generate or test hypotheses or to produce generalizable or transferable knowledge. The role of the patient advisors and those involved in the zine-making workshops was to inform the research design process, but they did not themselves contribute research data (see [22] for an example of similar work). Therefore, no ethical approval was required.

Figure 1 illustrates the recursive process of undertaking PPIE activities to identify the potential value in zines to address pain stigma. As a brief summary, PPIE 1 included an online meeting with patient advisors to shape the zine-making workshop design, which was followed by the facilitation of two zine-making workshops with a different group of people with lived experience who provided further feedback on the workshop design. PPIE 2 involved another meeting with patient advisors to seek their views on future research into zines.

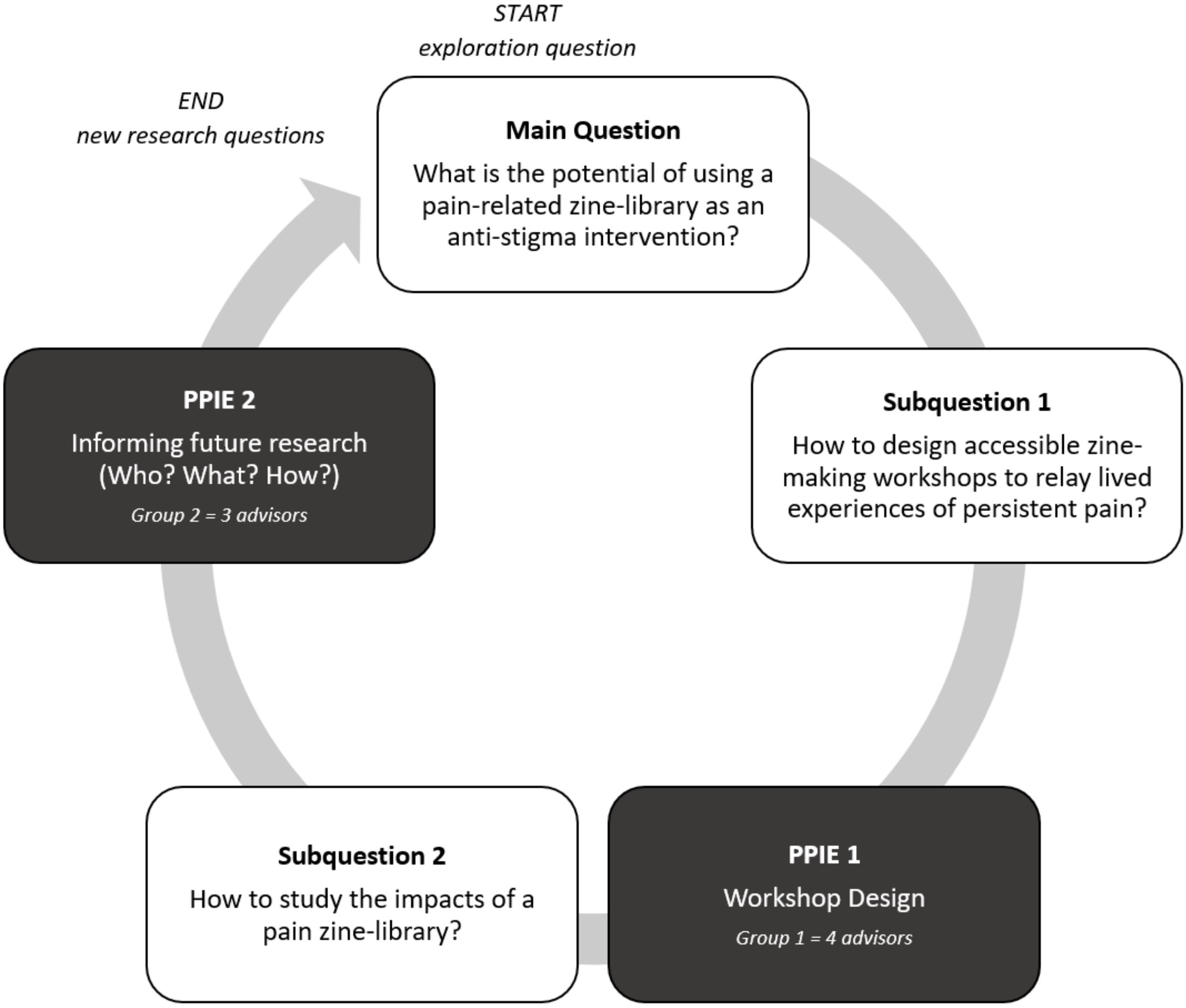

Figure 1: PPIE recursive process to inform the development and future evaluation of zines as an anti-stigma tool

Part 1: Developing pain-related zine-making workshops

PPIE process

Individuals living with persistent pain were invited to be involved in a single 1:1 meeting to shape the design of the zine-making workshop. Four people volunteered (PPIE group 1 on Figure 1). Two had recently attended a PMP at the pain management unit in London (United Kingdom). One had experience creating pain-related content for social media communities and one had experience facilitating health-focused zine-making workshops. The meeting was facilitated online by CL, who kept a written point form minutes, with consent. After a brief introduction to zines, the advisors were invited to discuss open questions such as: '*How to advertise for the workshops to target the appropriate population? How to make it accessible? How to gain consent?'*. The advisors were financially compensated for their time and expertise [24].

PPIE impacts

The relevance of zines lays in their accessibility. With this in mind, the patient advisors advocated for maximizing the inclusivity of the workshops. Given the Covid-19 pandemic and social distancing guidelines at the time this project was undertaken (January-June 2021), the workshops were delivered virtually. Unfortunately, due to the small scale of the project we were not able loan potential participants a device, although this should be considered in a larger scale project to ensure digital inclusivity. The advisors suggested sending basic materials packs for zine-making (e.g. papers, colour tapes, stickers, etc.) to participants who do not have access to these. This option was made available, although no request to access it was made. With similar inclusivity and accessibility concerns, the advisors suggested splitting the workshop into two parts, with one-week in-between, to accommodate each individual's needs. Most advisors recommended that each part should not exceed 90 minutes, including a 15-minute break. This allowed for participants to choose their pace during and between the workshops. During the first session, participants were invited to start a zine. They then had the opportunity to continue it in their own time in-between sessions and/or during the second workshop. The advisors highlighted that people could feel apprehensive about sharing their experience of pain and that communication through arts can feel intimidating for individuals who do not identify as artists. They provided guidance on initial activities to set the historical context of zines and to move beyond the idea that art is about beauty. It was also decided to allow reflective time for participants to consider what feels important for them to express in their zine, what theme they wanted to choose to guide the process, and who they would later share it with. The reflective activities allowed for interactions between the participants and started the creative process. The option to consent to share their zine was offered at the end of the workshop. Finally, as expressing pain and suffering can trigger distress, the advisors recommended that facilitators needed to be equipped to manage strong emotional responses to ensure a safe space for participants.

Two zine-making workshops were subsequently facilitated (Figure 1). The first was open to former patients who attended a virtual PMP delivered by the London pain management unit in the previous two months; these patients were not involved in the initial meeting to design the zine workshop. This zine-making workshop was facilitated by CL and another clinician, familiar with zines. Out of ten people approached, three persons volunteered to attend both sessions. The attendees did not suggest any significant change in the workshop design. The second workshop was organised in collaboration with the Footsteps Festival, a patient-led initiative that provides information, support and community activities for people living with pain and their carers [25]. This workshop was advertised online via social media. Adopting a similar structure, it was co-delivered with one of the patient advisor from PPIE 1 (Figure 1), who had experience in facilitating zine-making workshops and who identified as a zine artist. Eight people took part in the first session and six returned for the second. All participants were invited to share their zine, sending it by post or sending pictures by email. Four participants gave their consent to share their zine publicly [25].

Part 2: Shaping future research

PPIE process

Following the workshops, attendees were invited to act as advisors to give input into the design of future research to evaluate the potential impacts of zines on stigma. This involved a two-hour virtual group meeting. Three people contributed to this meeting (PPIE group 2 on Figure 1). A written guide was sent by email a week beforehand exposing the aims of the session. It invited the advisors to imagine that researchers had access to a wide collection of pain-related zines and to consider questions such as: *'Which population should we research and why?', 'What impact would we want to capture? How could we capture it?'.* All attendees were financially compensated [24].

PPIE impacts

The patient advisors identified two main sources of stigma that most powerfully affected them: self-stigma and stigma within their healthcare experiences. As such, they identified two groups to focus on for future research: people living with pain, suggesting that research should explore readers' sense of validation and belonging to a community; and healthcare providers, with an emphasis on General Practitioners (GPs) given their pivotal role in their healthcare journey. The advisors agreed that a zine-library could be used in healthcare education settings as an alternative exposure to patients' voices. They suggested that research should explore how reading zines influence GPs' understanding of the impacts of living with persistent pain on life, therefore if and how it affects their empathy towards people living with it.
When considering how to capture the impacts of reading zines, the advisors outlined that the sole use of quantitative methods would contradict the values of zines as a mean to highlight unique elements of each person's experiences. They agreed that qualitative methods would better capture the subtle nuances of the reflections triggered by the experience. They proposed questions such as:

'How often have the zines you have read been on your mind and what thoughts have you had about these'?

'Have you being doing or wanting to do things differently since reading the zines?'

These questions aim to identify the impact of zines on the reader's emotions and behaviours. The advisors encouraged careful consideration of the timing of data collection, emphasising benefits as well as limits in collecting data immediately after the contact with the zine-library versus after a short timeframe (e.g. two weeks).

After the meeting, the patient advisors for this stage (PPIE group 2) were invited to make a zine to share their thoughts about using a zine-library for future anti-stigma interventions. One reflective zine was consented to be shared (Artwork 1). Finally, one advisor also contributed as a co-author on this report (CS).

Discussion

This PPIE case report identified the potential value in zines to address pain stigma at multiple levels was identified by the patient advisors. PPIE informed the need to flexibly deliver zine-workshops to ensure they are inclusive and not themselves stigmatising or exclusionary. Patient advisors identified that future research should focus on qualitative methodologies to investigate the impact of zines on people with pain and healthcare providers. This project can inform larger scale delivery of zine workshops and libraries and future research to determine the impact of these initiatives in a manner that is rooted in what is important to people with lived experience.

The relevance of using zines lays in their accessibility and their potential to give access to a multitude of voices. With this in mind, the patient advisors strongly advocated maximizing the inclusivity of the workshops. The sense of inclusivity was concerned with practical (e.g. timing, information provided, advertisements, etc.), emotional (e.g. building a safe space) and financial aspects (e.g. accessing stationery, having a device and the internet for virtual workshops). It has been suggested that people living with persistent pain are more likely to be marginalised [26], to have lower or no income and that access to rehabilitation and pain services remains unequal [27]. Therefore, inclusivity is crucial to the design of zine-workshops and libraries should grow in diversity of narratives and formats. Sustained and meaningful involvement of people with lived experience of pain from a diversity of backgrounds is needed to continue to develop zine-libraries. This is consistent with calls to place a commitment to involving and engaging people from marginalized communities at the heart of pain research and practice [28].

This project highlights the potential impact of zines across different levels. At the *intrapersonal* level, zines are an opportunity for personal reflection [11]. For people living with pain, a multitude of voices within the zine-library may connect with their own experience, enabling a sense of shared meaning and belonging which could enhance individual resilience [29]. Indeed, this population is more likely to be socially isolated [26; 27] and often report feeling that others do not understand their pain condition [30]. Previous research has shown the importance of validation of pain to improve emotional regulation and relationship satisfaction, and to modify pain-related behaviours [31]. Related to this, the patient advisors identified that future research should explore the impact of zines on individuals' sense of validation.

In addition, displaying a zine-library may provide a safe environment for disclosure. Enabling people with experiences of stigma to move away from invisibility, disclosure is at the heart of *interpersonal* level interventions [32]. This is consistent with previous research suggesting the need to consider the role of intimate partners, family, friends and healthcare professionals in contributing to pain-related stigma [30, 33]. Disclosing various pain experiences, a zine-library may foster indirect contact between the stigmatized persistent pain population and the wider public. This has been shown to reduce prejudice in the context of anti-racism work [32].

The advisors suggested using zines as a tool to enhance health education and support GPs when working with people with pain. Empathy, validation, acknowledgment of diagnostic uncertainty and person-centred values and skills are at the heart of what people with pain expect from their care providers [34]. For complex reasons, clinicians' empathy tends to rapidly decrease throughout their training [35], and may be particularly likely when efforts to manage pain are unsuccessful [36]. Previous research has looked at the influence of arts-based interventions as an educational tool to develop healthcare professionals' empathy. For example, Schwind *et al.* (2014) [37] engaged nurses and students in arts-informed activities. Creating and observing arts supported nurses' self-awareness and critical reflection on their practice and promoted patient-centred skills. Ross and Lypson (2014) [38] also engaged medical students in an arts-based exercise, who reported that the experience triggered their reflection on disparities and stigma in healthcare practices. Reflective practice facilitates the understanding of patients' experiences and of one's own [39], the acceptance and management of clinical uncertainties [40], and the translation from theoretical knowledge to practice [41]. Therefore, at the *systemic level*, a visible and accessible zine-library could be used to design educational and reflective activities for healthcare providers.

Measuring the impact of anti-stigma interventions is however challenging given the complex and multi-layered social nature of stigma [11]. Future research using mixed methods and longitudinal approaches is likely needed to capture the impact of zines across different levels. For example, based on our PPIE work, a qualitative approach using one-to-one interviews and focus groups could reflect the impact zine makers' and readers' internal processes such as emotions, beliefs, and interpersonal attitudes. This could be used alongside longitudinal quantitative surveys to track self and external stigma over time. Future researchers will also be reminded that "*the social nature of arts activism requires that ideas not be developed in isolation*" [42, p.50].

Limitations

Co-production is particularly important in the context of anti-stigma interventions [43]. Despite valuing PPIE principles, there was unequal balance of power across clinicians/researchers and advisors in the current project. For example, the choice of zines as an art medium was driven by CL's previous experiences of using this medium. Other art forms could be relevant to design anti-stigma interventions. Similarly, zines could be used to research other health aspects. They were used as a data collection tool in the co-produced MadZine research project [44], exploring new understandings of mental health diagnoses, identities and experiences. Another limit of the PPIE activities was the absence of training opportunities for the advisors. For best PPIE practice, it is recommended to explore with patient advisors about any training needed to carry out their role and provide them with suitable opportunities to improve the quality of their involvement as well as their own development as desired [15]. Given that this was PPIE work and not research, the project was not intended to produce generalizable and transferable findings. Nonetheless, it is hoped that by disseminating the process and impact of this PPIE work, researchers can gain insight into how PPIE can be meaningfully undertaken in the pain field.

Conclusion

This paper highlights the value of undertaking PPIE in the development of an intervention that have the potential to target pain-related stigma. Zines, an art-based communication tool, can provided insights into the lived experience of persistent pain. Patient advisors highlighted the need for inclusivity to be at the centre of zine workshops and identified priority groups to study in the context of future research evaluating the potential of zines as an anti-stigma intervention. Future mixed methods research is needed to evaluate whether zines have this impact across levels.

Ethical Approval: This project does not meet the research definition established by the Health Research Authority (HRA) [23]. Therefore, no ethical approval was required.

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Conflict of Interest: No conflict of interest

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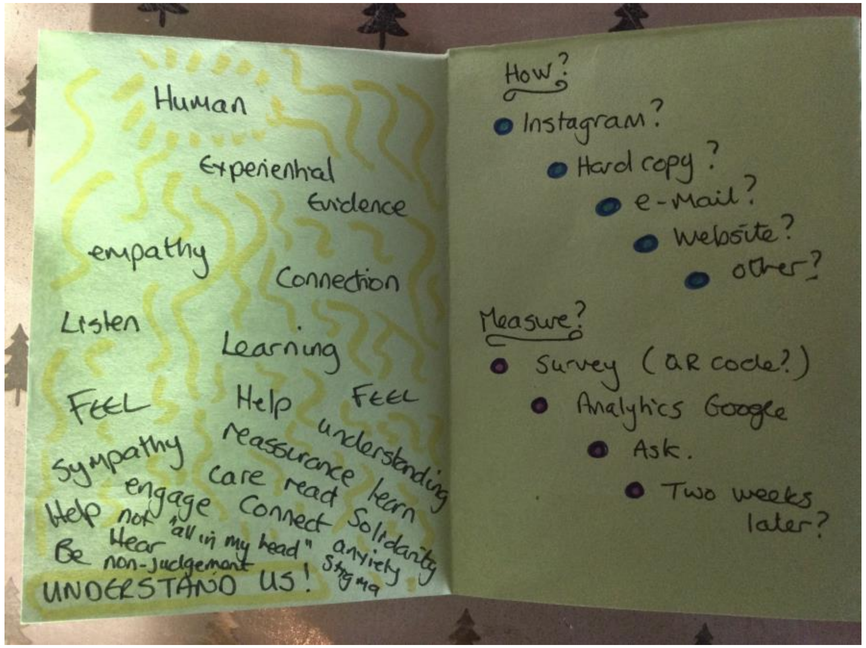
Artwork 1

Patient advisor’s zine reflecting on the potential of using zines for further pain anti-stigma research

(with consent)

1



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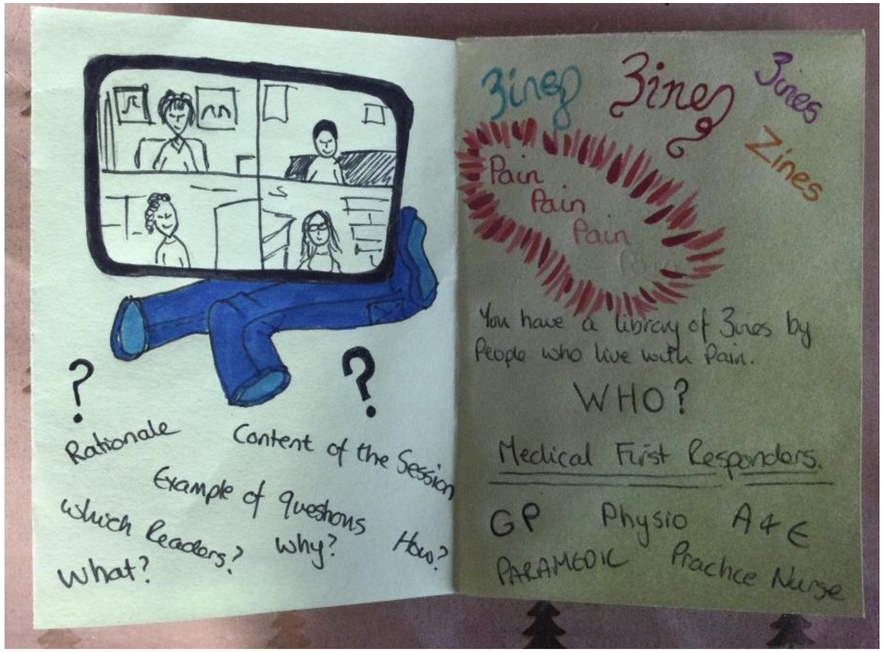

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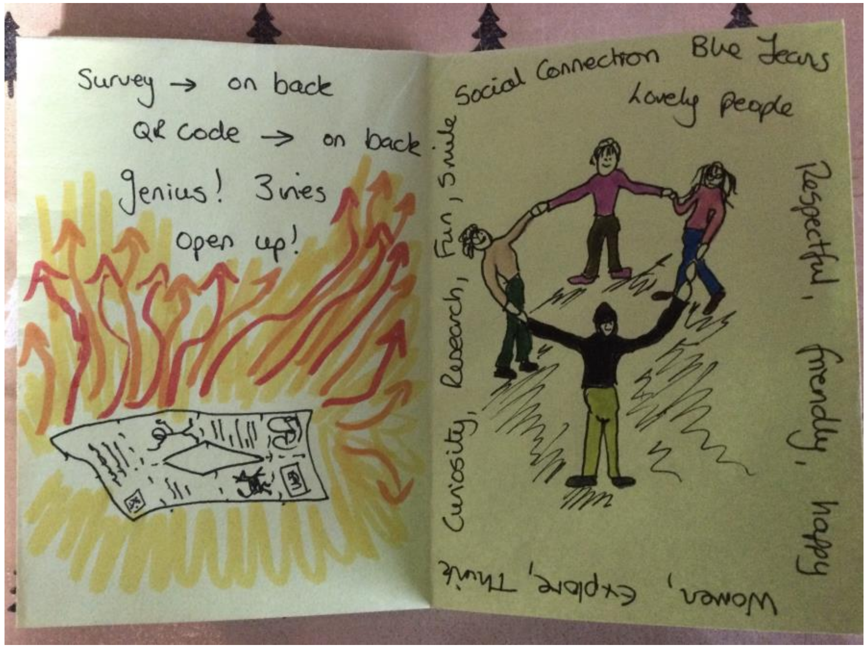

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