Joint allies: benefits and tensions of co-producing a prostate cancer app for, and with, the Black British African-Caribbean community

Abstract

In this paper we use a case study, the co-production of a prostate cancer app with, and for, Black British African-Caribbean communities, to discuss benefits and tensions of inclusive practice and allyship. We view our collaborators as joint partners, and joint allies, for the Black British African-Caribbean community. Here, we document the research process and highlight successful aspects of our collaboration such as mentoring, recruitment, ideas on the format and presentation of the app, supportive data collection practices, useful community feedback and promotion of the app. We also highlight points in the research process that in hindsight needed more discussion and careful negotiation. We end with some recommendations based on our experience.

Key words: co-production, prostate cancer app

Introduction

Funders of health research encourage researchers to include patients and public, or end users, in the design and conduct of research and this is becoming a mandatory part of funder requirements (Green, 2016). Whilst Black, Asian and Minority Ethnic (BAME) groups experience poorer health and encounter barriers to health care, many of these groups are excluded from involvement (Ocloo and Matthews, 2016). Often such groups are categorised by researchers as ‘hard to reach’. However, this label further marginalises, and stigmatises, the people who might fall within this remit thus a better term might be ‘seldomly heard’ (Beresford, 2013; Ryan, Hislop and Zeibland, 2017). Despite this, it is important to note that researchers often experience difficulties recruiting Black African and Black Caribbean men to prostate cancer research due to gatekeepers’ reluctance, and cultural perceptions about disclosing a cancer diagnosis (Bamidele et al., 2018). Bamidele et al. (2018) found that the best routes to recruitment were through National Health Service hospitals, snowball sampling, building rapport and trust, and being flexible regarding data collection (e.g., offering alternative modes such as face-to-face or Skype interviews). Funding bodies rarely address issues of power; thus, when public/patients/end users are included in health research, it is unclear to what extent they are treated as equal partners in the research process (Green, 2016).

In this paper we discuss the co-production of a prostate cancer app for, and with, a Black British African-Caribbean community in the midlands UK (n.b., African-Caribbean here refers to people of African ancestry with origins from the Caribbean, who may identify as Black British or mixed heritage). We use this as a case study from which to explore the benefits and tensions of co-produced research and allyship. Before doing so, we provide some detail about the study and the end product, the mobile application (app) ‘check tings out’

‘Check tings out’: a prostate cancer awareness raising app for Black British *African-Caribbean men*

The multi-disciplinary research team involved in the production of the app consisted of: five members of a Computing and Technology department; a psychologist; a prostate cancer consultant; two members of BME Cancer Communities; four members of Friends and Bredrins prostate cancer support group; a writer/actor/voiceover artist and a legal advisor, all based in Nottingham, UK. This group of people met regularly over the course of the app production and shared the associated tasks.

Initially, qualitative research was undertaken by the psychologist in the form of interviews with Black British African-Caribbean men with prostate cancer (n=10) and without cancer (n=10) to explore levels of awareness about prostate cancer; to determine men's knowledge and understanding about prostate cancer; to consider barriers to screening; and hear their experiences of treatment and recovery from prostate cancer (where relevant); and finally, to seek their advice about how best to deliver health promotion to Black British African-Caribbean men. Two focus groups were also conducted with members of awareness raising groups. The findings of this research were then used to inform the storyline of the app which was later reworked by a writer/actor/voiceover artist (see discussion, below).

The app provides users with prostate cancer information and evaluates their risk based on their profile. Each user receives personalised feedback based on their responses that are gathered while using the app. The integrated expert system layer within the app enables the evaluation of each user's risk of prostate cancer and adjusts the content in such a way that it persuades symptomatic men to seek medical advice (for further information see authors names, 2016a). The app is located at: https://play.google.com/store/apps/details?id=uk.org.isrg.android.pca and is also being promoted by our collaborators, BME Cancer Communities (https://www.bmecancer.com/) and by Friends and Bredrins prostate cancer support group (https://fabcancersupport.org/). The app was released in January 2020 and we do not currently have any engagement data to share[1]. Our aim is to promote the app further but currently Covid-19 has badly impacted upon our collaborators and progress has slowed as a consequence.

Allyship, co-production and inclusivity

Allyship denotes the phenomenon where individuals who are members of dominant social groups align themselves with a marginalized social group in order to address some form of oppression and move toward a system where power is equitable (Edwards, 2006). Heffernan (2018) highlighted that an ally is not directly impacted by the oppression that is tackled, yet they may benefit from the outcome. A growing body of research has recognised the importance of allyship and has begun to consider how to achieve empowerment in the design, development, delivery and evaluation of healthcare service provision (Happell et al., 2018). Within the context of health research, allyship has been extended to participation in research (INVOLVE, 2017). Allies use their senior positions in academia to enable opportunities for patients and public to become actively involved in research (Happell and Scholz, 2018).

A further concept, linked to public/patient/end user involvement in research, is that of co-production. Co-production entails a dismantling of the traditional power imbalances in

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[1] Android development requires a one-off fee of £25 (may have changed); then you must meet the app submission requirements as detailed by the store (these are also regularly updated, as the Android platform advances). The Play Store allows you to manage closed and open test releases, prior to final release.

research such that communities and marginalised groups are directly involved in research, rather than being the subjects of research (Beebeejaun et al., 2013). Co-production research is conducted in ways that promote and privilege the voice of the community and respects their cultural practices (Beebeejaun et al., 2013). However, co-production also acknowledges an element of mutual learning between parties involved in the research process drawing upon separate claims to knowledge (Pohl et al. 2010). Ocloo and Matthews (2016) propose six principles that should underpin co-production in relation to empowering patient and public involvement in healthcare improvement: recognising people as assets; building on existing strengths; reciprocal relations with mutual responsibilities and expectations; peer support and networks; dissolving boundaries and sharing control and responsibility; and acting as catalysts.

The concept of allyship in the research process is integral to the successful end-result, and impact, of collaborative research. Yet, whilst inclusive approaches to research are held up to be the ideal model, the practical implications of co-produced research are not well-understood (Green, 2016; Vaughan et al., 2019). The next section evaluates the success of such endeavours.

Inclusivity

Allyship and co-production partnerships might also consider inclusivity to culminate in an effective partnership. The goal of inclusive research, undertaken under the remit of allyship or co-production, aims to empower marginalised groups through representing their views in a respectful collaboration from research-design, conduct and eventual impact (Walmsley & Johnson, 2003). The ideal is that in doing so, health research with minority groups enables a redistribution of the typical hierarchies associated with more traditional research dynamics. However, previous research on allyship has highlighted that poor implementation of such initiatives can actually result in further marginalisation (Juntanamalaga, Scholz, Roper & Happell, 2019). For example, in the context of mental health consumers and allies, empowerment was linked to being part of the decision-making process. The study findings also highlighted that allies' lack of lived experience and understanding of mental ill health can result in a lack of shared understanding. This gap between both parties needs to be addressed through listening and making space for consumers (Juntanamalaga et al., 2019). Furthermore, attention needs to be paid to hidden agendas or motivations of allies. For example, consumers might feel that partnerships with allies are not genuinely supportive – rather, the allies need such partnerships to 'tick the involvement box' in policy making, furthering their own career. Aligned to this, the study findings highlighted that consumers may feel that ally perspectives dominate, and that true empowerment can only be achieved when they no longer need the partnership with allies (Juntanamalaga et al., 2019). One final point to note is that the binary categorisation of 'ally' and 'consumer' tends to reify differences. It may be the case that the consumer is also an ally, so this should be taken into consideration (Juntanamalaga et al., 2019). Similarly, Kluttz, Walker and Walter (2019) suggest that conceptually 'ally' evokes a binary and static position.

In the context of health research, allies need to provide opportunities for contributions from patients and the public. One study explored how mental health researchers enacted allyship with consumers (Happell et al. 2018). They found that securing research positions, or financial resources, for consumers to engage in research was a key step, meaning that their role as allies was often to raise the importance of such research with colleagues. Happel et al. (2018) noted that their participants believed that consumer-led, or co-produced, research was the ideal goal, possibly with the level of contribution being increased over time. However, reaching this point of equilibrium was, for them, viewed as only partially complete.

Perhaps, it is worth viewing allyship as a reciprocal relationship where both parties empower each other (Green, 2016). Vaughan et al. (2019) recommended that to achieve mutual support over a common purpose all parties need to be willing and accommodating of the others' needs. Scholz et al. (2019) highlighted the importance of: building the relationship; nurturing research skills; allowing better flexibility and timing of projects to ensure that collaborators' health is not impacted; and balancing research with other paid work. Scholz et al. (2019) acknowledged that bureaucratic deadlines are hard to shift (e.g., grant deadlines) but that planning research applications in advance might help to address this issue.

Working with BAME communities

Whilst Black British African-Caribbean communities may be highly motivated to engage in all aspects of research (Edge & Grey, 2018) the mechanics of co-produced research might not run smoothly. Researchers have highlighted issues that need to be taken into account when co-producing research. Vaughan et al. (2019) discuss issues such as: a consideration of the accessibility of where meetings are held; and proper payment of co-producer's time which involves a consideration of the fact that community researchers might be working part-time or may suffer financial risks as a consequence of payment if they are in receipt of any form of unemployment benefit. In a systematic review of Black, Asian and Minority Ethnic (BAME) inclusion in health research, it was argued that studies provided no description of the different activities they were involved in, nor did they identify any recommendations on best practice of BAME involvement (Dawson et al., 2017). Furthermore, the latter stages of the research process were identified as having the least BAME involvement (Dawson et al., 2017). Dawson et al. (2017) recommended the need for innovative ways of embedding BAME involvement in the latter stages of dissemination and the implementation of findings. Lane and Tribe (2010) highlighted some key issues with regards to inclusivity and BAME individuals. Firstly, do not assume that BAME individuals represent the views of everyone in the community they are representing, as a wide range of cultures, religions and views are typically present. Secondly, community leaders should not speak for a whole community as diverse views may exist, particularly in relation to gender.

Lane and Tribe (2010) suggested some practical guidance when working with BAME communities. The first step they outlined is to be prepared for community engagement and tailor your work to the community, considering any constraints. For example, be sensitive to different health beliefs and practices of the community; spend time building up relationships with community groups in order to acknowledge cultural, linguistic diversity, and complex social and political histories; and determine clear aims. Lane and Tribe also highlighted ethical practices, such as informed consent, may require a thorough consideration to ensure that everybody understands what they are expected to do and why. They also advise considering the need for an interpreter and providing food at events. The second step is to consider the practical issues associated with the research such as timing and facilities (e.g., disability access). The third step concerns the need to be responsive to community concerns and to ensure that engagement starts from the beginning of the collaboration rather than at the end point and that action is achieved post-community engagement. The fourth step is to disseminate the results to the community quickly and to seek evaluation of the results from them. It seems counter-intuitive not to involve BAME collaborators at this stage as they are best placed to disseminate findings in culturally appropriate ways using their own language skills.

One example of involving BAME members in research was the co-production of a culturally adapted family intervention with African-Caribbean individuals diagnosed with Schizophrenia (Edge & Grey, 2018). Here, African-Caribbean service users and their families helped to identify research priorities, designing the research questions, writing the grant application and disseminating the findings. The success of the research was aided by the ability to give temporary university contracts to community members, which enabled them to have access to academic resources and research methods training. A further example is the development of a diabetes prevention intervention for American Indian women which included American Indian women in the design and implementation of the intervention (Willging, Helitzer & Thompson, 2006). One key lesson learnt was the importance of having a clear rationale regarding the use of cultural elements. In particular, they stress the importance of adhering to a theory of how cultural content might contribute to behavioural change. Interventions need to attend to intra-cultural diversity issues so that American Indian women are not treated as having the same cultural reference points.

Study context: improving the poor prognostic outcomes for prostate cancer in Black British African-Caribbean communities

Black men, compared with White men, have a three-fold greater relative risk for prostate cancer (Chinegwundoh et al. 2006). Black African-Caribbean men in the United Kingdom, in comparison with other ethnicities, have the highest incidence rate of prostate cancer (Thompson, 2014). This serious health inequality was something that researchers at

Nottingham Trent University were keen to help tackle. We became aware of the work that Rose Thompson/BME Cancer Communities, and the prostate cancer group Friends & Bredrins (FAB), had achieved as grass-roots campaigners. BME Cancer Communities (BMECC) objectives are to preserve and protect the health of people, some of whom are Black, Asian and Minority Ethnic or from low income families living with, or affected by, cancer. They offer culturally sensitive practical advice, information, advocacy and support services. Their goals also include involvement in BAME cancer research and detection initiatives, and diversity training to improve service delivery of statutory bodies. Friends and Bredrins (FAB) is a support group which aims to help all Caribbean and African men, as well as all other ethnic minorities, and their families who are affected by prostate cancer. Furthermore, FAB continually strives to educate, inform, and improve delivery of their services. They positively engage with research professionals and organisations in order to promote Prostate Cancer Awareness.

In their ‘Hear Me Now’ campaign, BME Cancer Communities, supported by Friends and Bredrins, organised meetings which raised awareness amongst Black men but also alerted general practitioners to the higher risks in the Black British African-Caribbean and Black African community. One key point made was that “in order to commission services that meet the health needs of local communities, it is important not only to have meaningful engagement with the local community, but also for local communities to be approached in a way that respects their diverse skills and expertise” (Thompson, BME Cancer Communities, 2014 p.4). Our collaboration with BME Cancer Communities, FAB and Lisa Jackson (writer/actor/voiceover artist) is the focus of this paper. Our goal was to co-produce an app which raises awareness of prostate cancer and also highlights symptoms, risks, and the screening process. As academics, we held what could be categorised as a privileged status, but here we argue that we viewed our collaborators as joint partners and joint allies for Black British African-Caribbean communities in the co-production process. To clarify this point, whilst the academics were allies to our collaborators, our collaborators were simultaneously allies for the target audience of the app who are often those members of Black British African-Caribbean communities who have less power than our collaborators. However, the journey we took, and are still taking, had a number of benefits and tensions along the way (for all parties) which we discuss here in relation to the different stages of the app development.

Initial steps: funding

Our collaborators were involved right from the beginning when we sought the initial funding for the production of the app and the wider qualitative study that supported it. Thus, we were able to have their input in the design and execution of the research plans. We were conscious that we were building upon the work that both charities had already conducted and of the underlying principle that co-production was the best way to ensure that people's needs were better met if they were involved in an equal and reciprocal relationship with professionals, working together. Our collaborators highlighted that their role was vital (and often voluntary) in engaging with local populations but the cost to their organisations and members was high; thus, it was important to factor in adequate funding from the outset. We took this point on board and costed the grant accordingly.

Building trust and making contacts

From the early stages of our partnership, we spent time both in formal meetings and informal meetups to develop trust. The first author was the main contact with the collaborators, largely due to her role in collecting the qualitative data that informed the storyline to the app. As part of a team of White academics, the first author found that the informal meetings were a chance to explore aspects of conducting research as an outsider and to be educated by the collaborators on aspects of ethnicity and their experience with Black British African-Caribbean men who had prostate cancer. This meant that the first author was better prepared when conducting interviews with participants. For example, one issue we discussed was how being a White female researcher might impact upon conducting the interviews with our Black British African-Caribbean participants. Would it be better to have somebody from the community to interview the men? Ultimately, we decided that the researcher would undertake the interviews to limit the fear that information discussed would not remain confidential. Another issue key to successful community engagement is to understand the health beliefs and practices of such groups (Lane & Tribe, 2010). Spending time *via* informal meetings, the first author was mentored in the complex social, health inequality and political histories of the Black British African-Caribbean community. There was an attempt to incorporate such insights into her practice and engagement with the research participants. It is impossible within the space of this article to fully capture the wide-ranging nature of these discussions but they incorporated: sharing stories about the experiences of the Windrush generation; the racism people experienced; the over-representation of Black men in HM Prisons; and the discrepancies in health and the poor recording of ethnicity data. Of particular relevance to our research was the perception of health services held by some members of the Black British African-Caribbean communities which was occasionally negative in terms of their interactions with medics and the accessibility of venues. There is also a legacy effect from the scientific abuse of similar communities, for example the Tuskegee Study, where infected African Americans were neither informed about their disease status nor treated (King, 1992).

Our collaborators invited us to awareness training events and a range of other activities, all of which the first author attended. These sessions were useful as they provided an opportunity for members of the wider Black British African-Caribbean communities (including potential participants for the qualitative studies) to become aware of the research. These events were also a time when the first author began to hear stories from men affected by prostate cancer in their own terms.

At one awareness event, the first author was introduced to Lisa Jackson, a Black British African-Caribbean heritage writer/actor/voiceover artist (Mon0lisa Productions) who became integral to the production of the app. Lisa had developed a character, 'Patty Dumplin', which she had used in other health promotion materials. Patty Dumplin is a celebration of Jamaican heritage and culture, developed when Lisa was commissioned by the British Heart Foundation to engage Black British African-Caribbean communities[2]. Patty is a fun caricature whose mannerisms and sayings are modelled on Lisa's grandmother but who delivers serious health messages. This loveable character is known for her large frame, big hooped heart earrings, tilted black hat and catch phrases: 'Healthy Hearts are Wealthy Hearts', and 'Alright!' According to Lisa, the use of 'Jamaican patois wit and rhyme' and use of popular Jamaican proverbial sayings resonate well with audiences. The character, Patty Dumplin, was developed in consultation with the community and was featured on the local BAME radio station[3]. Feedback received on the character suggested community members liked the character. Lisa Jackson eventually became another member of our team and we sought additional funding (from an internal university Health & Wellbeing grant call) so that

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[2] BHF Link Recognition BHF Champion 2015 at Cardiovascular Conference Manchester https://www.bhf.org.uk/for-professionals/healthcare-professionals/bhf-alliance/bhf-alliance-awards-2015

[3] Hearts & Minds Summary Report 2011-2014 https://heartsandmindsnottingham.files.wordpress.com/2014/07/hm-project-summary-report-2013-2014.pdf

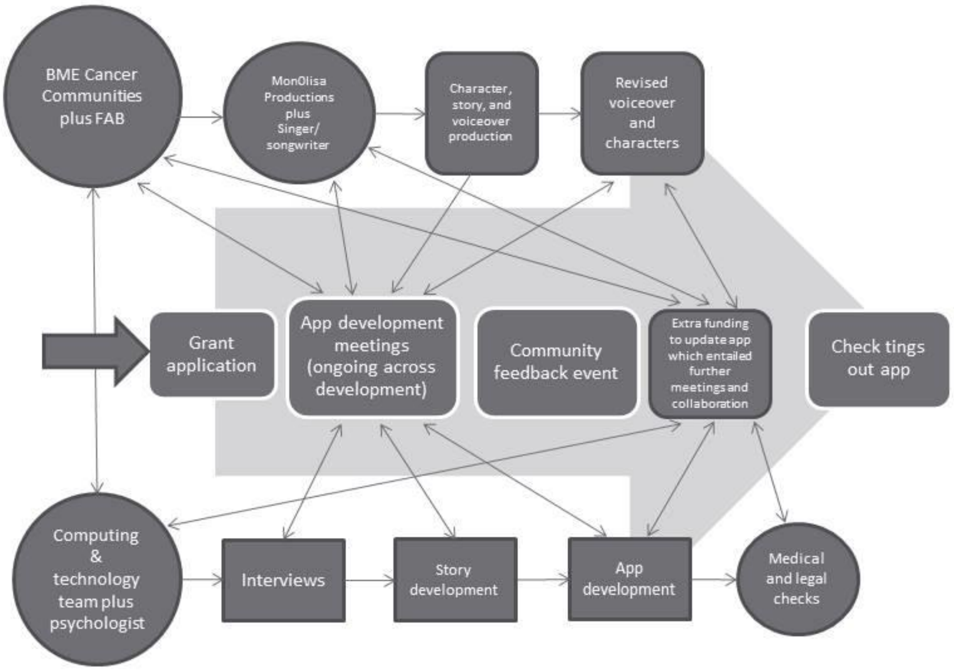
she could design the app to be set in a barber’s shop with her animated characters and voice becoming the focus of the information delivery.

Lisa Jackson developed the storyline so that it was ultimately delivered in a culturally sensitive way. For example, her characters take the central role in the app delivering information in Jamaican patois (with English captions) and using humour to engage end users. Jamaican patois is an English-based creole language with West African influences spoken primarily in Jamaica and among the Jamaican diaspora. This mode of communication may be used to perform ethnicity and negotiate community boundaries when necessary or desirable (Mair, 2003). As the majority of the Black British African-Caribbean community members and participants we worked with were of Jamaican heritage, we felt Jamaican patois was a valid medium to transfer knowledge *via* the app.

It is also important to acknowledge the commitment of others involved in the app. One key person was the consultant who checked the medical validity of the app content. This he did free-of-charge and at the weekend. The university also supported the app production and made sure that we adhered to legal requirements. Another unpredicted outcome was that one of the participants offered a song he had written and produced which plays in the background of the app.

Rycroft-Malone et al. (2016) argued that genuine collaboration through productive relationships takes time to establish and maintain. We would concur with this assessment. Typically timeframes to produce grant applications and research papers are tight. This means that at times it is not possible to adequately fulfil guidance on allyship ideals. However, if the working relationship continues these issues become easier to integrate and improve upon.

Chart to illustrate the progression of the app development



Conducting the qualitative research

The first author conducted interviews with Black British African-Caribbean men who had prostate cancer and also those who were cancer-free. Focus groups were also conducted with community members who were providing grass-roots cancer information and support. Our collaborators were crucial to the data collection process. Without their input it would have been extremely difficult and time-consuming to recruit a sufficient number of participants to the studies. Our collaborators arranged meetings with groups of men in order to ease the recruitment process. At such meetings, our collaborators vouched for our trustworthiness and the merit of the research we were co-undertaking. Our collaborators sign-posted potential participants to the study but also sometimes attended interviews (and waited in another room), or checked up on us whilst interviewing in a particular venue, and even held one interview in their own home. Our collaborators also provided us with other suitable venues to conduct the interviews and focus groups (at no cost). This investment of our collaborators' time was above and beyond any monetary recompense they received.

However, the process of recruitment and interviewing was not always smooth. Occasionally, communicating the research goals and ethical responsibilities fell short of best practice. For example, the community had generously set up a series of interviews for the first author at an African-Caribbean centre. However, the author arrived to find five men waiting to be interviewed when she arrived. This meant that the participants were aware that they were all taking part in the study, thus breaking issues of confidentiality. Furthermore, whilst interviewing, the first author was conscious that she was keeping other participants waiting. Conducting five interviews in a row is also not ideal, with no time for reflection or to take a break.

Another difficulty was a misunderstanding regarding the allocation of research roles: in particular, the distribution of the participant information sheets and consent forms. The first author believed that the collaborators had circulated these documents in advance so that the participants had a chance to digest and give informed consent to be involved in the study. However, on arrival at a focus group meeting the documents had not yet been given to the participants. Distributing this information at the start of the focus group was difficult due to the number of men present (too many for a focus group) and took time due to some men needing the researcher to read the sheets to them before gaining consent. Some members of the group were initially wary of being involved in the research (some not wanting to sign the consent form with their real name) and the first author was placed in a difficult position where she had to manage the situation as best as possible. The focus group was also arranged in an evening, tagged onto the end of a meeting the men had attended. Therefore, the men, all of whom had prostate cancer, were already fairly tired and some had to leave during the session.

This experience led the first author to reassess the mechanics of the research process. As an academic, the problems encountered were hard to deal with but highlighted the need for her to better explain issues of data collection and ethical practice with the collaborators in advance. Working practices from grass-roots organisers and the community are different to the protocols of academia and, retrospectively, more time should have been spent discussing these issues in advance so that both parties were more aware of potential issues. The issue of confidentiality was something that caused further tension and we return to this later in the paper.

Another issue was that the collaborators bought gifts for the participants (with the funding they received from the grant) that they helped to recruit. The first author was informed that this was more culturally appropriate than giving money to recompense for their time. However, the grant did not cover reimbursement to the few participants that the first author recruited herself. This disparity across participants was something that left an uncomfortable feeling. Furthermore, it meant that we should have allocated more money to our collaborators for this. This was another lesson learnt – to discuss such issues in advance and make sure that equity was achieved in future and that both parties were aware of the different frames of reference they were working from and to work out some agreed protocols.

Feedback

Once we had produced the first version of the app, we held a community feedback event. Our collaborators were crucial to inviting members of the Black British African-Caribbean community to the event, which included key community leaders but also participants and their family members. We promoted the event in the usual ways but were also advised to also use alternative forms of invitation such as text reminders close to the event.

The feedback from the community gave us a solid base to work from in revising certain aspects of the app. These included: a critique of the Jamaican patois as this did not represent the way that other Caribbean men spoke (to address this we added the English captions); and that some of the characters were deemed too 'scruffy' (these have been tidied up in the latest version).

We wrote a press release to two media outlets. We were shocked when the response from one was that they viewed the app as racist. We believe the criticism was due to the representation of the characters and voice in the app. We can only infer that the media were critical of the way that the characters were styled and the use of patois as we have no detailed feedback. It may be that this presentation of characters was viewed as stereotyping members of Black British African-Caribbean communities and an assumption that the app did not have the level of community involvement, and approval, that it did. To address this issue we discussed the feedback with our collaborators and decided that when the app was officially released, media outputs would heavily focus on the fact that the app was co-produced and approved by the Black British African-Caribbean community. It is unclear how one could avoid the criticism. Effectively, the critique of racism, potentially on the grounds that the characters were stereotypes, is based on a decision made by members of the Black British African-Caribbean communities. As allies, white researchers should be reluctant to reinforce any stereotypes of the community that they are supporting. However, our collaborators felt that this criticism reflected a power imbalance such that their expertise and experience of what worked at the community level were misunderstood by those not embedded in the community. Culturally and linguistically appropriate health education materials, such as ours, are designed to be sensitive to cultural beliefs and practices (Anderson et al., 2003). In a systematic review of the effectiveness of such health promotion, only four studies were identified and the majority of these were conducted among African American populations. As with our app, these cases drew upon styles of dress and music between the actors and the target audience. Whilst there was some evidence that these culturally sensitive health promotions were effective, the conclusion was that there was insufficient evidence to determine the effectiveness of this mode of intervention (Anderson et al., 2003). Our decision to stay with the way that the characters were presented reflected the trust that we had in our collaborators and the evidence that suggested this worked well in other health promotion campaigns they were involved in. Should we have changed the presentation of the characters on the app we believe that our collaboration would have been damaged. Decisions such as these will need careful consideration by other White researchers who are in a similar position. One suggestion is to pilot ideas with the target community prior to their implementation in order to confirm the confidence in decisions and advice that are made by collaborators.

Research dissemination

The ideal for conducting research with co-producers and allies is that they are involved in the research process from the planning stage to conducting, writing and disseminating research outputs. We have tried to honour this with some success and some failure.

One finding from the qualitative research focused on a barrier to screening identified by the participants in the study. This barrier was also acknowledged, and tackled, by our collaborators at their own training events. Specifically, digital rectal exams were seen as problematic due to the fear that being examined in this way could be linked to being viewed as gay. Notably though, the participants (and our collaborators) were aware of this issue and were all working hard to address and overcome this barrier. The participants argued that it was something the community needed to come to terms with and that education was required to tackle any misconceptions. We believe that we successfully attended to this issue within the app. However, once a paper was written based on research findings (authors, 2016b) and circulated to the collaborators prior to submitting for publication, the reference to this barrier was viewed as damaging by one of the collaborators who felt that it could be construed as Black British African-Caribbean men's own fault for having such views. Thus, whilst the collaborators and participants themselves had highlighted this as a barrier, they were reluctant for this aspect to be raised in the publication. However, the way that this issue was reported and analysed did highlight that participants themselves were taking ownership and addressing this barrier. After some discussion with the first author, the collaborator acknowledged that the judgement they made was a consequence of the title of the paper which included a quote from one of the participants ("I really don't want a doctor to be examining, you know, my back bottom": the digital rectal examination as a barrier to prostate cancer diagnosis in Black British African-Caribbean men) (this was subsequently changed) and not based on a thorough reading of the paper. The tension decreased once the details of the discussion regarding the barrier were considered, and the problematic title was revised to something that better reflected the positive engagement that participants had in relation to the barrier – notably that they were coming to terms with the need for the digital rectal examination. From further discussions with the collaborator in question, the first author acknowledged the clumsiness of the initial title and the assumptions that might follow from this. The paper in question was circulated to our collaborators in advance but they were not co-authors (although they were acknowledged). In future, findings and publications should ideally be discussed further in advance and co-published to avoid any misunderstandings and to highlight potential problems. This current paper is co-authored and as a consequence has been a smoother venture. However, in making revisions, the first author had to request an extension to accommodate this process of feedback. Luckily, the special issue Editors were very accommodating (as one would anticipate) whereas this might not be the case if co-produced papers are submitted elsewhere. This need for extra time is a general issue about co-produced papers that needs highlighting to journal editors.

Another critique from our collaborators about the above research publication (authors, 2016b) which discussed the barrier of the digital rectal exam, was that we acknowledged one collaborator by name but another through a general description. This was due to their dual role as collaborator and also as a participant in one of the focus groups. If they had been named in the paper the confidentiality of some participants of the focus group would have been compromised. Again, responsibility for this misunderstanding should have been more carefully discussed by the academics prior to writing the paper in order to clarify the reasons for the omission.

Promoting co-allies

In line with allyship principles, one positive outcome of our collaboration was that the first author put forward Rose Thompson, Director of BME Cancer Communities, for an Honorary Degree of Doctor of Social Science in recognition of her significant contribution to BAME community engagement in preventative cancer care which she was awarded in 2017.

Release and promoting the app

The app credits all parties involved in its production at the beginning and end. Furthermore, we have recently licensed the app such that our collaborators have the ability to host it on their charity websites in order to promote it. This strategy would seem the most sensible approach to promoting the app – to the people from the people. However, we have fallen short of being able to provide intellectual property rights to the community due to the difficulties associated at an administrative level. Specifically, our legal advisor stipulated that for us to be able to include the collaborators in the intellectual property rights, this needed to have happened from the beginning of the research and could not be achieved retrospectively at the end point of the research. This was something that we were unaware of but will ensure in any future collaboration.

Discussion of best practice

Our case study highlights some issues pertinent to allyship and the co-production of research. Co-production and allyship comes with benefits and tensions stemming from the different frameworks we operate within. On balance, the experience of co-production has been a learning curve, particularly for the first author. Notably, the second author and his team have a wealth of successful experience with co-production in the field of technology and special needs education. In line with others, we aimed to promote and privilege the voice of the community (Beebeejaun et al., 2013; Juntanamalaga et al., 2019). As advised by others, time was spent building the relationship with our collaborators (Scholz et al., 2019; Vaughan et al. 2019) such that it was possible for open discussion and the ability to hear critical points from all parties. However, as highlighted above, university bureaucracy impacted on our ability to fully achieve best practice (for example, the failure to secure joint Intellectual Property Rights). In future collaborations we know to start this process at the beginning of the partnership.

Our recruitment strategy for the qualitative studies which underpinned the storyline for the app successfully reached our goal of recruiting Black British African-Caribbean men and two focus groups. Researchers typically struggle to recruit Black African and Black Caribbean men to prostate cancer research groups (Bamidele et al., 2018) and we believe our success in this aspect was due to our collaborators role in facilitating this. Other researchers should consider this route in addition to those outlined by Bamidele et al. (2018) which included recruitment through National Health Services and snowball sampling.

Our attempt to deliver the information on the app in a culturally sensitive way was grounded in advice from our Black British African-Caribbean collaborators. However, initial feedback from a few Black British African-Caribbean men highlighted that this did not represent the way that other Caribbean men spoke, a similar point also highlighted by Willging, Helitzer and Thompson (2006). The Black British African-Caribbean community is diverse and interventions must try to meet specific cultural experiences and language practices

(Livingston, Pierce and Gollop-Brown 2013). Future versions of the app could include other modes of communication representing the wider Caribbean context. Furthermore, as the majority of our participants were Jamaican, future collaborations could usefully aim to employ a more diverse recruitment strategy to engage a more heterogeneous sample (Bamidele et al., 2018). As for our discussion of media criticism that the app was racist, we defer to our collaborators from the Black British African-Caribbean community as their expertise and knowledge of what works best should be privileged.

We hope that this paper has highlighted how crucial it is that co-production operates equitably with marginalised groups. Our research would not have been possible without our community co-researchers. Designing health promotion tools for marginalised groups works best with their input from designing the research questions and throughout the research process. Below, we outline some issues for other researchers to consider:

- Whenever possible, begin discussions well in advance of securing funding and starting the research process
- To avoid tokenistic involvement, in-depth discussions about pertinent issues need to be raised in a timely manner so that different agendas are clear and thought through
- Try to foster equal respect and work hard at developing trust. You might not get this right the first time but if trust has been fostered these issues can be better tackled in future co-productions

- Make sure that adherence to best practice in academic research and ethical practice are understood and explained well in advance with research training provided where appropriate

- Acknowledge and promote co-producers/co-allies and aim to share intellectual property rights as best practice
- Aim to write and disseminate research collaboratively including research papers where possible

On balance, we believe that we have successfully co-produced a useful awareness raising app in partnership with our allies, for Black British African-Caribbean men. We finish with some comments from our collaborators. Roydon Allen, member of Friends & Bredrins, at our last meeting expressed his opinion that the app was a really useful tool to raise awareness and that the collaboration has proved successful. Furthermore, Lindsay Thompson from BME Cancer Communities said, “having recently becoming directly involved in the collaborative activities of BMECC, NTU and FAB, I am truly impressed with our working relationship in terms of engagement and involvement from a community perspective. I am positive that our future working relationship will bring about the positive outcomes and meaningful impacts as a result of our combined resources.” Finally, Lisa Jackson stated that, “throughout the partnership my work, grown from grass-roots activist underpinnings, was valued on an equal footing with the academic team members. My past experience with other health promotion initiatives was that I was not trusted if the product was questioned in relation to its authenticity and relevance when issues of, for example, racism were levelled at the characters I developed. In contrast, in this collaboration I felt that I had an equal voice at the table due to the respect I was given which acknowledged the careful validation of the characters which were developed through extensive fieldwork. This gave me confidence to provide a voice from the community for the community. Furthermore, my time was valued through a consideration of the accessibility of meetings and through appropriate financing of my contribution."

Conclusion

Our case study involving the co-production of a prostate cancer app, 'check tings out', highlighted a number of benefits and tensions of inclusive practice and allyship. Our collaboration highlighted the importance of all parties being involved from the onset and noted how the development of trust was crucial for effective working relationships to avoid miscommunication in the research process. As allies, we learnt some valuable lessons for future practice including the need to discuss data collection procedures in more detail to avoid problems at this stage and to disseminate findings with our collaborators in line with best practice.

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