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Development of a Cultural and Linguistically Sensitive Virtual Reality Educational Platform to Improve Vaccine Acceptance within a Refugee Population: The SHIFA Community Engagement-Public Health Innovation Program

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-051184
Article Type:	Original research
Date Submitted by the Author:	14-Mar-2021
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Keywords:	Paediatric infectious disease & immunisation < PAEDIATRICS, QUALITATIVE RESEARCH, Community child health < PAEDIATRICS

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3 **Development of a Cultural and Linguistically Sensitive Virtual Reality Educational Platform to Improve**
4 **Vaccine Acceptance within a Refugee Population: The SHIFA Community Engagement-Public Health**
5 **Innovation Program**
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49 **Keywords:** vaccination, refugee health, community engagement, virtual reality, education
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52 20 **Manuscript Word Count:** 4502
53
54

55 **Figures and Tables:** 6
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Number of References: 23

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3 25 **ABSTRACT**
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6 **Objectives:** To combat misinformation, engender trust, and increase health literacy, we developed a
7 culturally and linguistically appropriate virtual reality (VR) vaccination education platform using
8 community-engaged approaches within a Somali refugee community.
9
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11 **Design:** Community based participatory research (CBPR) methods including focus group discussions,
12
13 30 interviews, and surveys were conducted with Somali community members and expert advisors to design
14 the educational content. Co-design approaches with community input were employed in a phased
15 approach to develop the VR storyline.
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17

18 **Participants:** 60 adult Somali refugees and 7 expert advisors who specialize in healthcare, autism
19 research, technology development, and community engagement.
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21

22 **Setting:** Somali refugees participated at the offices of a community-based organization, Somali Family
23 Service, in San Diego, California, as well as at a community health fair and online. Expert advisors
24 responded to surveys virtually.
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26 35

27 **Results:** We find that a CBPR approach can be effectively used for the co-design of a VR educational
28 program. Additionally, cultural and linguistic sensitivities can be incorporated within a VR educational
29 program and are essential factors for effective community engagement. Finally, effective VR utilization
30 requires flexibility so that it can be used among community members with varying levels of health and
31 technology literacy.
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33 40

34 **Conclusion:** We describe using community co-design to create a culturally and linguistically sensitive VR
35 experience promoting vaccination within a refugee community. Our approach to VR development
36 incorporated community members at each step of the process. Our methodology is potentially
37 applicable to other populations where cultural sensitivities and language are common health education
38 barriers.
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List of Abbreviations:

50 CBPR: Community based participatory research

CHW: Community health worker

MMR: Measles, mumps, and rubella vaccination

SFS: Somali Family Service

VR: Virtual reality

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ARTICLE SUMMARY

Strengths and Limitations of this Study

- Community based participatory research plays an important role in the creation and customization of necessary health interventions for vulnerable populations. The qualitative aspects of this study provide in-depth information that can help to address complex vaccine hesitancy issues among Somali refugees.
- This study uses community co-design in the development of a virtual reality health education for Somali refugees. Community-engagement methods such as community co-design are novel and effective strategies that employ the community itself for refugee health promotion and for new technology development.
- This project is a pilot study with a small sample size which will need to be expanded to truly understand the effect of our virtual reality health innovation on refugee vaccine perceptions and behaviors.

INTRODUCTION

Over 300,000 refugees enter the United States every year. While refugee resettlement has increased over time, events as recent as 2015 mark one of the largest exoduses of forced human migration, sparking a crisis as countries struggle to cope with the influx and the social and economic demands that coincide with human resettlement [1]. What is largely missing in the public discussion is an appreciation that refugees face extraordinary challenges throughout their migration process from origination to destination. One challenge in particular – the access to proper healthcare - is critical, both for those that have been resettled in the past and those who have recently arrived [2]. The other challenge is to collect and monitor healthcare data that can be accessed and disseminated to resettled communities for public health monitoring [3]. In recognition of these challenges, important questions range from how to efficiently meet the healthcare demands of a growing population that is effective and sustainable to providing an engagement that uses culturally specific resources that simultaneously enhances health education and drives an increased level of trust in the local healthcare system [4].

Upon resettlement in Western countries, many Somali refugees were faced with the widespread diagnosis of autism, a developmental disorder which was unfamiliar to them prior to migration [5]. On one hand, among a community cluster of resettled Somali children in Minneapolis, the prevalence of autism has exceeded 3% and has eclipsed the national average of 1.9% [6]. On the other hand, this specific refugee community was targeted by anti-vaccination activists and the propaganda that vaccination is a cause of autism. This misinformation led to concern by Somali parents and distrust in the healthcare system, which has resulted in a propensity for vaccine hesitancy and non-acceptance [5,6,7]. A lack of effective messaging towards what does cause autism and the dissemination of anti-vaccination propaganda were successful in decreasing vaccination rates in the Somali refugee population in Minnesota from 92% to 42% over the span of a decade [7,8].

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3 Effective healthcare education relies on various principles for building essential skills, including
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5 95 communication, assessing the accuracy of information, decision making, planning, goal setting, and self-
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7 management [9]. At its core, health education must be simple, retained, and must be assimilated within
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9 those factors relevant to a given individuals biases and acceptances towards the delivered message [9].
10
11 New digital innovations such as virtual reality (VR) has emerged as a tool to provide an enriching and
12
13 immersive learning experience that promotes absorption in both acute conditions such as anxiety and
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15 post-traumatic stress disorder, and chronic conditions such as tobacco cessation as well as for medication
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17 100 compliance [10-13]. The ability for VR to increase information retention and to change health behaviors
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19 by engaging users in a non-healthcare environment makes VR a potentially valuable platform for visual
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21 health education. Therefore, our primary aim was to develop a customized, culturally and linguistically
22
23 appropriate VR educational program specifically focused on pediatric vaccinations, and to leverage
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25 community based participatory research models and community co-designs to build, test, and deploy VR
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27 105 at the community level among a group that are known to be vaccine hesitant or vaccine resistant.
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34 **METHODS: STUDY DESIGN**

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36 SHIFA (Arabic for 'healing') is a community innovation program to design, deploy, and utilize new
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38 110 healthcare innovations with an inclusive model of community engagement. Within the current program,
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40 community based participation was incorporated along three complementary approaches [14]. These
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42 include:
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- 46 1) To define the health care access barriers in a resettled refugee community with a focus on
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48 pediatric vaccination.
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51 115 2) Incorporate a community-based participatory model to develop the virtual reality content
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53 with community member co-design.
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- 55 3) Develop a virtual reality technology that is customized with cultural, linguistic, and religious
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3 sensitivities to provide appropriate health education.
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5 Qualitative feedback was derived through focus group discussions, interviews, and surveys developed by
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8 120 the investigators and was completed by community members and experts for analysis during each phase
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10 of technology development. Focus groups and interviews were conducted by Najla Ibrahim and Samantha
11
12 Streuli. Najla Ibrahim is a Somali woman who holds an MPH degree and is an expert in community public
13
14 health issues. Samantha Streuli is a white woman who is a PhD candidate in anthropology at UC San Diego
15
16 and who has been working with the Somali community for three years. The majority of focus group and
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18
19 125 interview participants were unknown to Samantha and Najla prior to the research project, though some
20
21 were acquaintances from previous work within the Somali community.
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25 ***Ethics Approval Statement***

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28 This study was approved by The University of California San Diego Institutional Review Board (Protocol
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30 130 #171434).
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34 ***Patient and Public Involvement***

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37 The Somali community was involved in the research from its inception and were regularly consulted as
38
39 the research was developed. Focus groups and interviews with the community informed the development
40
41 135 of research questions, which prioritized the experiences and interests of the Somali community. We
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43 consulted with community members and community leaders when designing and conducting the study
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45 and developing survey, focus group discussion, and interview questions to determine outcome measures.
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47 Somali community members were also involved in the recruitment to the study, as much of the
48
49 recruitment happened via word-of-mouth. The results of the study will be presented to participants and
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52 140 other community members, who will be further consulted via focus groups on how to best disseminate
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54 results.
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Participants

Inclusion/Exclusion Criteria

145 We identified groups of Somali individuals for community participation and VR co-design. Participants
11 were required to be members of the Somali community in San Diego, California who were over the age of
12 18 and were either 1) Somali refugees; 2) Somali immigrants; or, 3) US-born Somali Americans. We
13 14 15 16 17 18 19 20
21 150 community and in pediatric health; 3) leaders within the Somali community.

Setting

27 San Diego County is the 3rd largest metropolitan area in California and the 12th largest resettlement area
28 29 30 31 in the United States. The organization responsible for the development and execution of the program is
32 155 Somali Family Services (SFS), a fiscal sponsor for the East African Collaborative of 8-community
33 34 35 36 37 38 organizations that aims to outreach, educate, and enroll refugees and immigrants in health insurance
39 40 41 42 43 44 45 programs. This specific community predominantly resides in City Heights, a subdivision of San Diego
46 47 48 County that has a population of 75,000 individuals. Socioeconomic statistics of this region includes a
49 50 51 52 53 54 55 median household income of \$39,330 (national median \$55,322), 40% are immigrants and/or refugees,
56 160 with 31% having an education level of a bachelor's degree or greater [15].

Recruitment

59 Somali individuals were recruited via telephone and through word-of-mouth by Somali Community Health
60 Workers (CHWs) and peers. Our target participants were: a) parents of children between 0-2 years of age,
b) pregnant, or c) planning to become pregnant in the next two years; however, we included those Somali
community members interested in issues of autism and/or vaccination regardless of parental status. All

1
2
3 participants consented to have their names and contact information collected for future
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5 correspondences. This information was securely stored in an encrypted file and only used to re-contact
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7 participants who agree to be re-contacted. The research objectives, research participants' rights, and
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9 description of how data would be used were explained to all participants prior to participation. All
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12 170 participants provided verbal consent, which was approved by The University of California San Diego
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14 Institutional Review Board (#171434).
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19 Expert advisors were identified by the SHIFA project leadership team according to their particular areas
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21 of specialization. Advisors signed consent forms to participate in the iterative development of educational
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23 175 content.
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26 27 28 ***CBPR and Community Co-Design***

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31 Our CBPR approach involved community members in each step in the design, iterative testing, and
32
33 development of culturally and linguistically appropriate health education content. This approach to CBPR
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35 180 in the Somali community builds upon public health work previously done within refugee communities
36
37 [16]. We developed a community co-design methodology that uses the principles of design thinking
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39 combined with community-based research to enable participants to be directly involved in the design and
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41 creation of content and products that are developed to benefit them [16-17]. This co-design methodology
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43 was inclusive in that community members were asked to participate within content curation and to lead
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46 185 certain aspects of VR development.
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50 51 ***Phased Approach to Virtual Reality Development***

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54 We merged each aspect of CBPR and community co-designs within a phased approach to VR development
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56 (Vendor: INVIVO, Toronto, Canada). These phases included:
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3 190 **Phase 1:** CBPR approaches to assess community needs and concerns important to pediatric vaccination.
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6 **Phase 2:** VR modality determination for script development. The modality consisted of the type of VR
7
8 experience and the script development included the specific educational content.
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11 **Phase 3:** VR Prototype and iterative feedback from storyboards, 2- and 3-dimensional animation, and
12
13 visual and audio experiences that incorporate VR design elements including those factors that allow users
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16 195 to engage at different levels of health literacy.
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18 **Phase 4:** Final VR Product and Testing
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21 The objective within VR development was to use those tools and devices that were available to the
22
23 community-at-large and to ensure cultural and linguistic sensitivities were incorporated.
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30 200 ***Data Collection and Analysis***
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32 All data were collected electronically via tablet or computer at the time of focus group discussions,
33
34 interviews, and surveys. Focus group discussions and interviews were either recorded and transcribed, or
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36 extensive notes were taken on a computer in the event that groups or individuals declined to be recorded.
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39 Analyses were conducted thematically and iteratively using the content of the surveys, focus group
40
41 205 discussions, and interviews during the phased approach for VR development. This approach utilized five
42
43 steps: 1) familiarization, 2) coding, 3) theme development, 4) defining themes and, 5) reporting (Miles &
44
45 Huberman, 1994) [18]. During the process of familiarization, all sections of the interviews, focus group
46
47 discussions, and surveys relating to the experience of utilizing VR were extracted. Coding was performed
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49 using MAXQDA software. Emergent themes from each phase of development were defined and reported
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53 210 in order to inform the subsequent development phases.
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3 The primary data coder was SAS. To ensure a rigorous evaluation of the data, a subset of transcripts was
4 also coded by AM. In order to achieve consensus on codes, AM and SAS engaged in recurring discussions
5 on the coding process. The analysis was further tested during discussions with expert advisors. The
6 consensus was reviewed and approved by all investigators. Specific quotations were chosen by SAS to
7 represent emergent themes in the data.
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16 RESULTS

17 This program began in April 2019 and product testing is ongoing. Figure 1 illustrates the phased approach
18 to development and iterative testing. In total, 67 individuals (7 advisors, 60 Somali community members)
19 provided feedback during each phase of VR development and participated within the community-co
20 design.
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31 *Community-based Participation*

32 The first step in our community engagement process was to hold a series of 3 focus groups exploring
33 topics of interest to the Somali community including vaccination, autism, pediatric health, and technology
34 (n = 18 Somali community members). Based on this initial feedback from the community, the project team
35 held a design workshop to create a series of 3 story ideas for the VR. These ideas were then brought to
36 the Somali community in the form of another design workshop where the community evaluated the
37 suitability of the provided stories and suggested changes. 4 Somali community members (2 Somali
38 community health workers, 1 Somali woman, and 1 Somali man) participated in this design workshop to
39 develop the general framework of a story. Information learned from the community was then used to
40 develop a first iteration of a script. This script was then tested for cultural and linguistic suitability and
41 vaccine-promotion potential with 17 Somali women from ages 26-78 and was followed by a discussion
42 with a prominent male community leader to again assess the cultural and linguistic appropriateness of
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3 235 the content to promote vaccine education. Finally, a 2-dimensional prototype of the VR animation was
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5 developed with a Somali voiceover (Figure 2) and was tested with 24 community members in order to
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7 determine the effectiveness of the messaging in promoting vaccination and to assess cultural and
8
9 linguistic elements of the storyline.
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14 240 ***Phased Approach to Virtual Reality Technology Development***

17 ***Phase 1:*** CBPR approaches to assess community needs and concerns important to pediatric vaccination

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20 The Somali community focus group discussions were broken up into three separate sessions, each of
21
22 which focused on a particular area of community interest (Table 1). The first focus group discussion was
23
24 centered on health concerns of the community, and participants cited autism as a major concern, as
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26 245 well as language barriers that pose a significant problem when engaging with the medical system. In
27
28 addition, participants brought up issues of trust which were tied to poor communication.
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33 The second focus group discussion explored issues of pediatric health. Participants provided information
34
35 about pregnancy, childbirth, pediatric care, and parenting. The central theme of this focus group
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37 250 discussion was issues of trust within the medical system, with many mothers indicating that while they
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39 highly valued their doctors' opinions, they also preferred to do their own research. Mothers relayed to
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41 us their desire to receive health education in their own language from a trustworthy doctor.
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47 The third focus group discussion was centered around issues of vaccination and technology. Participants
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49 255 once again indicated issues surrounding trust in medical systems and their desire to make their own
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51 educated health decisions. Additionally, participants stated that they would like to receive more
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53 detailed information about how vaccinations work:
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3 “If they could show how the vaccine works in the child’s body and what it does – if it can be
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5 260 visualized.”
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10 “That before the vaccines are given to our children, for it to be explained to us what the risks are
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12 - the sided effects, and the benefits. When we compare the two, then make a decision.”
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16 265 Themes that emerged from interviews with 3 Somali parents also included concerns about autism,
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18 medical trust, and the desire to learn more about vaccination.
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24 **Phase 2:** VR modality determination for script development 25

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27 *Modality determination:* The project team consulted extensively with Somali CHWs to determine an
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29 270 appropriate modality, and chose 360-video due to the ability of this format to be experienced using virtual
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31 reality headsets, smart phones, or computers in order to make this VR program widely accessible to all
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33 members of the Somali community.
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37 *Script development:* Open-ended survey responses from Somali community members regarding the
38
39 three potential storylines indicated that an older Somali male doctor would be most suitable to deliver
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41 275 health information in our story, as this character would evoke feelings of trust and respect. Somali
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43 community members favored a scene where a Somali mother could be shown talking to her doctor –
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45 this way they could see themselves as a character in the VR story and could see their questions and
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47 concerns being addressed directly. The open-ended survey responses from community advisors
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49 indicated a preference for a storyline with a strong focus on family and supported the story concept of a
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51 Somali mother asking questions to a trusted physician. This information was used to develop the initial
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53 script.
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5 Six members of the expert advisory board reviewed the initial script. Advisors were asked to answer a
6 series of six open-ended questions and provided insightful answers that assisted with script
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10 285 development (Table 2). Specifically, when advisors were asked for their overall impressions of the story,
11 they stated:
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17 “Overall, I like how the story flows and the way in which the educational components are
18 presented.”
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23 “I like the simplicity of the conversation with its effective focus on the key messaging of the
24 value of the timely vaccination to help raise healthy kids.”
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30 We conducted a community focus group discussion during the script review process to engage the
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32 295 community. Community members were asked to assess how culturally appropriate the storyline was,
33 what they would like to change, how impactful the story was, and how they would personally design the
34 content. During this focus group discussion, participants agreed that the story was clear and easy-to-
35 follow; however, as additional questions were asked about story flow, the feedback turned to autism.
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38 We found that even when we did not mention autism, the false association between autism and the
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43 300 measles, mumps, and rubella vaccine (MMR) came up as a topic of discussion. Many community
44 members said that they were concerned about autism and the MMR vaccination. One woman asked:
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48 “if MMR doesn’t cause autism, why did I see my child stop talking immediately after getting the
49 MMR?”
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3 305 The participants agreed that the VR must address the autism question, and that they would prefer to
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5 learn this information from a doctor character in the VR storyline.
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10 Community members were also asked to take a brief survey after reviewing the script. This survey
11
12 included questions about attitudes toward vaccination as well as vaccination planning. Notably, there
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14 310 was an 18% increase in participants who endorsed being “very comfortable” with MMR vaccination
15
16 following script exposure. Additionally, those who said they were “not at all comfortable” with MMR
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18 vaccination decreased by 12% following script exposure. There was also a 17% increase in those who
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20 stated they would allow their child to receive the MMR following script exposure (Table 3).
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26 315 **Phase 3: VR Prototype and iterative feedback**

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28 Three expert advisors provided feedback on the storyboard and prototype that focused on where
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30 characters were positioned (i.e. husband next to wife), color scheme, and highlighted the need to describe
31
32 the immune system’s function in order to retain scientific accuracy in the communication of vaccination
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34 information.
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40 The prototype (Figure 2) was tested with the Somali community in the context of an in-person focus group
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42 discussion and surveys that took place both in-person and online. Participants in the focus group
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44 discussion were asked a series of open-ended questions about their experience with the prototype. The
45
46 primary focus of this discussion was analysis of the storyboards and stylistic elements of the VR experience
47
48 (e.g., color preferences, imagery, portrayal of characters). Participants indicated that they highly valued
49 325
50 the Somali voiceover and preferred to include the discussion of autism in the final VR storyline, as its
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52 exclusion would raise more questions for the community. The participants also felt that the father
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3 character in the VR storyline seemed somewhat excluded and should be standing near his wife to signal
4 support.
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8 330 All participants who reviewed the prototype agreed that the inclusion of culturally appropriate characters
9 and a Somali voiceover maximized the educational experience. 13/24 (54%) participants stated that the
10 prototype made them either more comfortable or much more comfortable with vaccination than they
11 were before exposure to the prototype. 20/24 (83%) participants stated that they would recommend
12 MMR vaccination to members of their community following exposure to the prototype. Additionally,
13 335 21/24 (88%) said they planned to vaccinate their children following exposure to the prototype.
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25 *VR design factors:* The key VR design elements that were incorporated within each phase of VR
26 development include passive, non-intrusive experiences, a dynamic and interactive visualization, and
27 prompts that promote the user towards self-reflection.
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34 **Phase 4: Final Product and Testing**

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38 The final product is a four minute 360-video animation (<https://youtu.be/NS8GvtxnIk0>) available in Somali
39 and English languages. It can be viewed online using a tablet, a smart phone, or with VR goggles. Settings
40 include a Somali home populated by a family, and a doctors' office. In the animation's introduction, we
41 meet the expectant mother who states that she is expecting her first child and is trying to make decisions
42 about vaccination. Figure 3 illustrates in screenshots each of the 4 chapters in the VR experience. We plan
43 to test the final product using an A/B testing model with the Somali community wherein the A group
44 receives the VR education and the B group receives a basic English-language educational video about
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3 vaccination. Both groups will be surveyed before and after exposure to the educational materials to assess
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5 350 changes in attitude toward vaccination and willingness to vaccinate.
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10 11 **DISCUSSION** 12 13

14 The main results of the SHIFA program can be summarized as follows: 1) a community
15 participatory research model can be effectively translated for the co-design of a VR educational program
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17 355 with community members involved in each phase of technology development; 2) cultural and linguistic
18 sensitivities can be incorporated within a VR pediatric immunization educational program and are
19 essential factors for effective community engagement; and 3) effective VR utilization requires flexibility
20 that can be used among community members with varying levels of health and technology literacy. To
21 the best of our knowledge, our VR development is the first such health innovation for vaccination
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23 360 education designed by a community of refugees known for vaccine hesitancy.
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36 ***Refugee Learners – Vaccination & Autism*** 37

38 This community has common barriers to effective education such as a lack of information and
39 information that is not culturally and/or linguistically appropriate to drive understanding [19]. Regarding
40
41 365 immunizations, many parents and caregivers in this community already possess medically inaccurate
42 information. We have previously determined that within this refugee community the reason not to
43 immunize has resulted from misinformation and the perception that vaccination results in autism.
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45 Although MMR vaccination rates have fallen in the Somali community (from 92% to 42% over the span of
46
47 a decade [7,8]) rates of autism and pediatric learning impairments have remained high (1:32 Somali
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49 370 children have autism compared to the national average of 1:54) [20-21]. While these results do not
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3 support the link between vaccination and autism, many parents are still convinced of an association
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5 between MMR and autism. Given these results, it is important to take into consideration the mental and
6
7 emotional state and the ideation that arises from associating vaccinations with autism. Within this
8
9 community health engagement related to immunization requires education focused on the importance
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11 of vaccinations for newly arrived refugees, and a re-education among those who have previously elected
12 375 not to immunize. In this context, we performed a community health assessment and identified the drivers
13
14 for a low rate of vaccination in the Somali community ranging from cultural and language barriers, distrust
15
16 in the healthcare system, and the misinformation that vaccination results in autism. Recognizing these
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18 drivers for low immunization rates in this community, our observations for the mechanisms for how VR
19
20 affects behavior changes include: content that is culturally relevant, stimulates an awareness and
21
22 expectation for what vaccines do and do not do, and provides an immersive experience leading to
23 380 information retention [22].
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33 ***VR CBPR and Co-Designs***

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36 385 In addition to the mechanisms for how VR affects behavioral change, several design factors must
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38 be maintained when considering who interacts with the VR technology and especially among immigrants
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40 that may have varying levels of health and digital literacy. Within our program, most community members
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42 experienced a positive interaction with VR. There are several plausible reasons for our observations.
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44 Through community co-designs, we leveraged key design factors including a non-intrusive experience
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46 (users learn in their own environment), a passive interaction (content that is visual, audio, and depicted
47 390 versus reading), a dynamic storyline that builds upon previous experiences and uses known environments,
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49 and promotes self-reflection by allowing the user to introspect and contemplate during the VR experience.
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Because we recognized the importance of culturally and linguistically appropriate educational materials to deal with issues of low health literacy and medical distrust, we included community-based approaches in each phase of our development. The results of focus groups and surveys conducted within the community revealed several important considerations for the development of our VR storyline. For instance, community members were much more comfortable receiving information from a trusted doctor character. Community members also felt it necessary to include direct and clear information about the lack of relationship between autism and vaccination in our storyline. This was in contrast to our expectation and that doing so would reinforce this misinformation. Following design workshops with the Somali community, we tested the program that they helped to co-design within the community in order to address its cultural and linguistic appropriateness as well as its ability to promote vaccination behavior. We also tested the VR storyline with a team of subject matter experts who evaluated the scientific accuracy and usability of our design. In our community testing, we found that many Somali community members felt the VR storyline engendered trust, was relatable, was educational, and was convincing. Several focus group and survey participants stated that they planned to vaccinate and to recommend vaccination to others following exposure to the VR. Our testing with our panel of experts found that our content was user-friendly, easy to understand, and scientifically accurate.

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While we appreciate that community co-designs are an important methodology for how a new technology is designed, a foundation of CBPR is necessary to harness community involvement. To employ CBPR, we engaged community members throughout every step of the process. Before developing the idea for the VR storyline, we engaged the community in a series of three focus groups to better understand their needs, strengths, and interest in collaboration. Focus group discussion questions were open-ended and allowed for participants to bring their interests and concerns into the conversation. Information learned from these engagements was used to begin to develop the culturally and linguistically appropriate

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3 storyline for the VR. Community members were also continuously engaged throughout the development
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5 of the VR storyline through community co-design.
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10 420 It is our plan to leverage the educational curriculum as well in future deployments of VR. Due to
11
12 the constraints of COVID-19, we are currently exploring the possibilities of using telehealth and other
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14 digital communication platforms to safely and effectively deploy the VR into the community. Addressing
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16 vaccine hesitancy is especially relevant within the context of COVID-19, as vaccination rates for
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18 preventable diseases have dropped significantly since the beginning of the COVID-19 crisis [23]. There are
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21 425 also concerns about the potential of misinformation related to COVID-19 vaccination that is especially
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23 relevant for an underserved community that is largely excluded from vaccine clinical trials and
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25 communities that have a history of vaccine hesitancy.
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31 **Limitations**

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34 Our community feedback and focus group may represent a convenience sample for those that are
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36 more apt towards vaccine acceptance, and therefore may not completely capture all concerns among
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38 those who are vaccine hesitant. While this represents a potential selection bias, our method to include a
39
40 wide range of community members as well as internal and external advisors may enhance internal validity
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43 435 by incorporating a heterogenous group for community input. Community based participation and
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45 community co-designs at each stage of VR development from the initial idea through completion of a VR
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47 animation may enhance external validation by including the key components related to cultural and
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49 linguistic sensitivities within the phased approach for VR development. Finally, a perceived shift from
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51 vaccine hesitancy to vaccine acceptance at this point is subjective and requires real-world validation and
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54 440 prospective follow-up confirming vaccine delivery.
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CONCLUSION

We employed community-based participatory approaches, and community co-design to develop an innovative vaccine educational technology with Somali refugees using VR. By combining new technology-enabled approaches with the needs, interests, and expertise of Somali community members, we have created a methodology that can address vaccination beliefs and behaviors in a vaccine hesitant refugee population. Future research will include an assessment of the efficacy of the VR platform on vaccination rates over time, as well as continued community engagement for the development of additional VR content which can increase health literacy within underserved populations.

ACKNOWLEDGEMENTS

We first extend our sincerest gratitude to the Somali community for their inspiring engagement in this project. Next, we would like to thank Fadumo Jama, Ahmed Dahir, and Sahra Nor for their assistance with participant recruitment, facilitation of community engagements, and translation and interpretation services. Finally, we are grateful to Dr. Ahmad Bailony and Karen Henken for their guidance and input on this project.

CONTRIBUTORSHIP STATEMENT

Samantha Streuli and Sanjeev Bhavnani had full access to all of the data in the study and took responsibility for the integrity of the data and the accuracy of the data analysis. All authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Concept and design: Streuli, Ibrahim, Sharma, Esmailian, Sezan, Sahid, Bhavnani

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3 **Acquisition, analysis, and interpretation of data:** All authors
4

5
6 **Drafting of the manuscript:** Streuli, Bhavnani
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9 465 **Critical revision of the manuscript for important intellectual content:** All authors
10

11
12 **Literature search:** Streuli, Ibrahim, Sharma, Bhavnani
13

14
15 **Obtained funding:** Sahid, Bhavnani
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17
18 **Administrative, technical, or material support:** Sahid, Bhavnani
19

20
21 **Supervision:** Sahid, Bhavnani
22

23
24 470 **Final approval of the version to be published:** All authors
25

26 **Role of the Funder/Sponsor:** The funders had no role in the design and conduct of the study; collection,
27 management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript;
28 and decision to submit the manuscript for publication.
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37 475 **COMPETING INTERESTS**
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39 Carrie Farrell was a paid consultant on the project from inception until August of 2019. Alex Marchetti is
40 a former employee of technology partner INVIVO and her engagement with the project began while she
41 was with that organization in 2018. Sanjeev Bhavnani discloses Scripps Clinic Grants for clinical trials
42 related to machine learning and technology designs in cardiovascular imaging, being a Pfizer Health
43 Information Technology Advisory Board member on strategies related to health information technology,
44 being a Bristol Meyers Squibb Digital Health Advisory board member on strategies related to digital health
45 technologies, being an Anthem AI Consultant on projects related to cardiovascular care, being a Proteus
46 Health Chair DSMB on digital medication monitoring in hepatitis C, being an American College of
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3 Cardiology Innovations Advisory Group Principal investigator and committee member on various
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5 485 innovation projects in cardiovascular care, having Analytics4Life Stock options as a scientific advisor on
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7 artificial intelligence in cardiovascular diagnostics, and having Blumio Stock options as a scientific advisor
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9 on new technology designs in hypertension. Markie Esmailian discloses US patents in Illumesense Inc.,
10
11 using data analytics and machine learning algorithms for clinical decision support for alternative health
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13 therapies. Markie Esmailian is also Founder of IllumeSense Inc. as majority shareholder and principle. All
14
15 other authors declare that they have no relevant or material financial interests that relate to the research
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17 490 described in this paper.
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25 **FUNDING**

26
27 Alliance Healthcare Foundation i2 Innovation Grant 2017 (Grant #18-34728477)
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31 495

32 **DATA SHARING STATEMENT**

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34 Data are deidentified participant data and are available from the corresponding author upon request.
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37 Reuse is not permitted.
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TABLE 2. Questions and Responses from Project Advisors

Questions Asked to Advisors	Salient Responses
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TABLES

TABLE 1. Focus Group Questions and Responses from Somali Community

Category and Questions for Community Members	Salient Responses
Session 1: General Health	
Examples of questions asked in focus groups	
“What are some of your community’s biggest health concerns in the U.S.?”	<p>“Autism.”</p> <p>“One of the biggest health problems that people have that I forgot to mention is that most people don't understand a lot of English.”</p>
“What do you find not trustworthy within the health care system?”	<p>“Lack of good communication...especially in primary language.”</p> <p>“Health insurance!”</p>
Session 2: Pediatric Health	
Examples of Questions asked in focus groups	
“Do you trust your doctor’s recommendations for your child’s health?”	<p>“Yes, whatever recommendation the doctor gives me, I have to take it.”</p> <p>“I mean I always think it's obviously for a good reason, but for me, I think I always do my own research before I automatically assume that's what's best for me. If it's something very serious like [the doctor] saying for example 'you need a surgery,' that [I] automatically would be like 'let me get another opinion from another doctor.’”</p>
Session 3: Vaccination	
Examples of questions asked in focus groups	
“What are the topics or things that you would like to know about in relation to vaccines?”	<p>“If they could show how the vaccine works in the child’s body and what it does – if it can be visualized.”</p> <p>“That before the vaccines are given to our children, for it to be explained to us what the risks are - the sided effects, and the benefits. When we compare the two, then make a decision.”</p>

Table 1: Sample questions and salient responses from exploratory focus groups indicated that parents were very concerned about autism and that they found it difficult to trust the healthcare system due to lack of communication in their primary language. While parents trusted certain doctors, they also highlighted the importance of doing their own research to understand their children’s health. Parents also expressed a desire to understand how vaccines work within the body and what the risks and benefits are of vaccination.

<p>1) What are your overall impressions of the story? What did you like the most about the story? Is there anything that you think should change in the story?</p>	<p>“Overall, I like how the story flows and the way in which the educational components are presented. I also think it’s a great idea to have the story centered around a meal, as it seems culturally relevant and helps make the situation relatable to users.”</p>
<p>2) Have you noticed any inaccuracies in scientific and medical facts in the story?</p>	<p>“Based on my past feedback, I am glad that this story has been selected. I like the simplicity of the conversation with its effective focus on the key messaging of the value of the timely vaccination to help raise healthy kids.”</p>
<p>3) Was the story clear and easy to understand? Did the story flow naturally?</p>	<p>“No.”</p> <p>“No, from my knowledge all of the content presented is accurate.”</p>
<p>4) Was the story culturally appropriate? Was the cultural component balanced throughout?</p>	<p>“Very clear and flowed in a way we would use in teaching in general. Very logical progression of information.”</p> <p>“Yes, the story is clear and flows very naturally.”</p>
<p>5) Was the story convincing? Does it have a potential to change attitudes of vaccine hesitant parents?</p>	<p>“One of the things I liked about this story is the emphasis of the great Somali family bond that can be pivotal in achieving the goals of this project to leverage the great trust Somali parents put on their relative and educated community members.”</p> <p>“Yes, the story was culturally relevant and appropriate.”</p>
<p>6) In your opinion, does the story increase knowledge?</p>	<p>“I think it gives the information about immunization, the science behind it, and does not focus on the controversies, which have not been supported by medical data.”</p> <p>“Yes. I would just make sure we really take advantage of VR when we show the visuals inside the body and how vaccine’s function within the immune system.”</p>
	<p>“Yes, it stays with the facts in a positive way, in a healthy environment with the families.”</p> <p>“It can, depending on the background of the parents and audience and their desire to benefit from such educational program.”</p>

580 **Table 2:** Sample questions and salient responses from engagement with project advisors. Advisors enjoyed the clarity and flow of the storyline as well as finding it culturally relevant and appropriate. They also believed that the story had significant potential to increase vaccine knowledge.

TABLE 3: Survey following initial script exposure

How comfortable are you with MMR vaccination?	%	How comfortable are you with MMR vaccination?	%	Would you get MMR for your child?	%	Would you get MMR for your child?	%
Very comfortable	52%	Very comfortable	70%+	Yes, I would	65%	Yes, I would	82%+
Somewhat comfortable	24%	Somewhat comfortable	18%-	I would consider it	23%	I would consider it	12%-
Not at all comfortable	24%	Not at all comfortable	12%-	I don't know	6%	I don't know	0%-
				No, I would not	6%	No, I would not	6%

585 **Table 3:** This table shows the results of a survey of 17 Somali mothers following exposure to the initial
 590 script for the VR. + indicates % increased following exposure to the script, - indicates % decreased
 following exposure to the script.

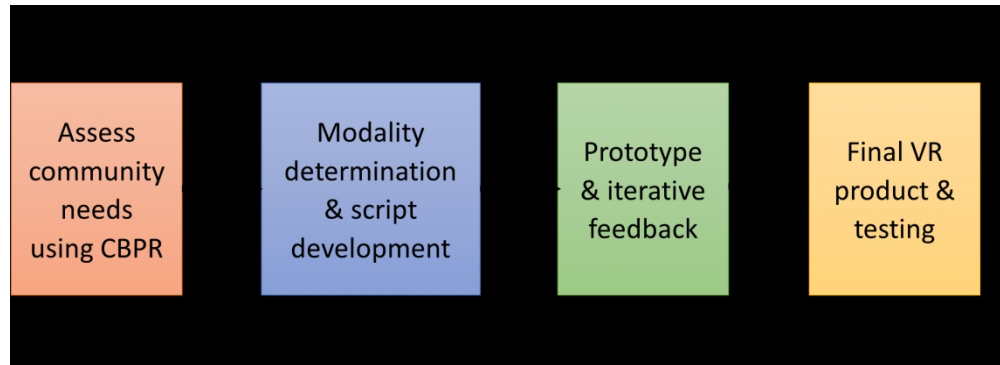
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600 **FIGURES**

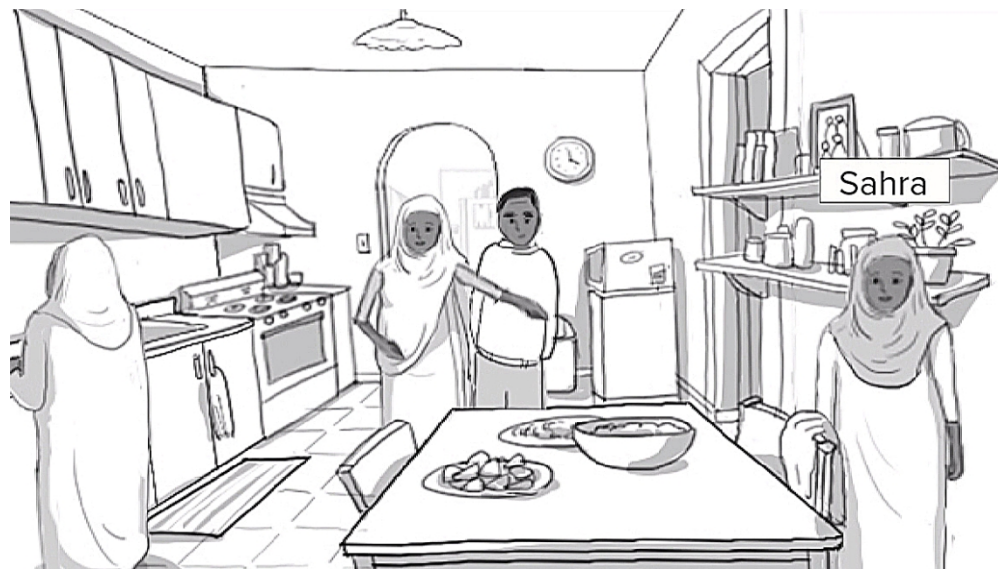
605 **Figure 1:** Phased approach to VR development. Assessment of community needs began in April 2019 in advance of the development of the VR. Iterative testing took place throughout 2019 and 2020, with some gaps in testing due to the restrictions of the COVID-19 pandemic. The final VR product has been completed as of June 2020 and is currently being tested with the Somali community.

610 **Figure 2:** Still frame from prototype. The prototype consisted of a motion storyboard with a voiceover which was translated into Somali for presentation to the community.

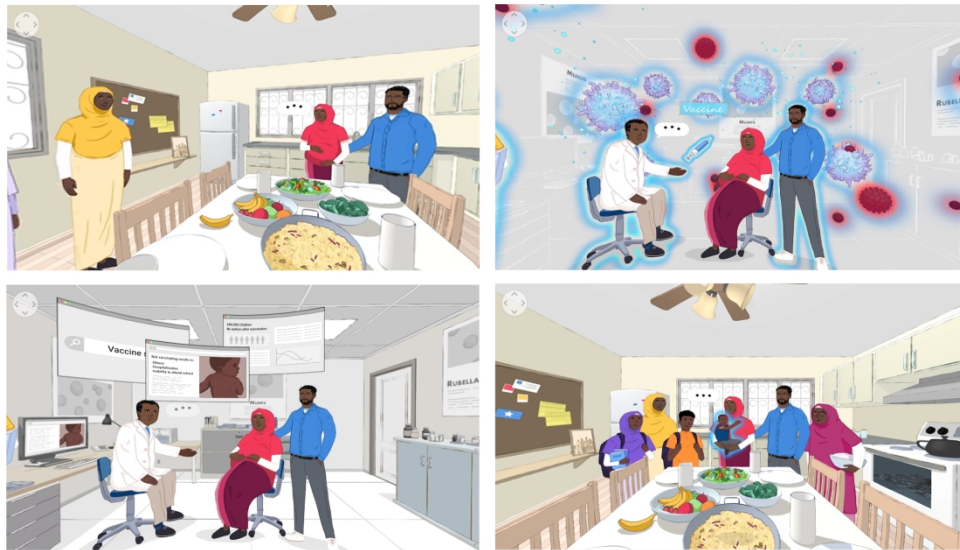
615 **Figure 3:** Top row: Chapters 1 and 2 of the VR story. Bottom row: Chapters 3 and 4 of the VR story. In chapter 1 of the animation, the expectant mother, her husband, and her sister visit the doctor's office and learn about measles, mumps, and rubella (MMR). In chapter 2, the family learns how the immune system works. In chapter 3, the family learns from the doctor what the MMR vaccine does and how it works. In Chapter 4, the doctor explains to the family the risks and benefits of MMR vaccination, including a statement debunking the association between autism and vaccination. Finally, the 360-degree video concludes by showing the new mother and her family – including the new, healthy baby – and the new mother states that after learning all the facts, she has decided to vaccinate her child.



Phased approach to VR development. Assessment of community needs began in April 2019 in advance of the development of the VR. Iterative testing took place throughout 2019 and 2020, with some gaps in testing due to the restrictions of the COVID-19 pandemic. The final VR product has been completed as of June 2020 and is currently being tested with the Somali community.



Still frame from prototype. The prototype consisted of a motion storyboard with a voiceover which was translated into Somali for presentation to the community.



Top row: Chapters 1 and 2 of the VR story. Bottom row: Chapters 3 and 4 of the VR story. In chapter 1 of the animation, the expectant mother, her husband, and her sister visit the doctor's office and learn about measles, mumps, and rubella (MMR). In chapter 2, the family learns how the immune system works. In chapter 3, the family learns from the doctor what the MMR vaccine does and how it works. In Chapter 4, the doctor explains to the family the risks and benefits of MMR vaccination, including a statement debunking the association between autism and vaccination. Finally, the 360-degree video concludes by showing the new mother and her family – including the new, healthy baby – and the new mother states that after learning all the facts, she has decided to vaccinate her child.

Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 3

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Page 6
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	Page 7 Line 102

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale**</p>	<p>Page 8 line 120</p> <p>Page 9 line 160</p> <p>We employed CBPR and community co-design in order to develop educational content that was created by and for the communities for whom it was intended. We used focus groups, interviews, and surveys in order to triangulate our data and to include the voices of the community in as many ways as possible.</p>
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Page 8 Line 121
<p>Context - Setting/site and salient contextual</p>	Page 8 Line 135

factors; rationale**	
<p>1</p> <p>2 Sampling strategy - How and why research</p> <p>3 participants, documents, or events were</p> <p>4 selected; criteria for deciding when no further</p> <p>5 sampling was necessary (e.g., sampling</p> <p>6 saturation); rationale**</p> <p>7</p> <p>8</p> <p>9</p> <p>10</p> <p>11</p> <p>12</p> <p>13</p> <p>14</p> <p>15</p> <p>16</p> <p>17</p> <p>18</p> <p>19</p> <p>20</p>	<p>Page 8 line 125.</p> <p>Somali community members were chosen in the manner that they were because we recognize the importance of including the entire community in research. There is a strong oral tradition in Somali culture and parents often ask advice from extended family and community when making decisions about healthcare. Thus, we found it necessary to engage individuals of all ages and genders who spoke English and Somali to guide the educational material and provide their input.</p> <p>Expert advisors were chosen in order to provide us with another view of the issue from a technical angle so that we could better create something that could be realistically delivered to the community.</p>
<p>21 Ethical issues pertaining to human subjects -</p> <p>22 Documentation of approval by an appropriate</p> <p>23 ethics review board and participant consent,</p> <p>24 or explanation for lack</p> <p>25 thereof; other confidentiality and data security</p> <p>26 issues</p> <p>27</p>	<p>Page 9 Line 150</p>
<p>28 Data collection methods - Types of data</p> <p>29 collected; details of data collection procedures</p> <p>30 including (as appropriate) start and stop dates</p> <p>31 of data collection and analysis, iterative</p> <p>32 process, triangulation of sources/methods, and</p> <p>33 modification of procedures in response to</p> <p>34 evolving study findings; rationale**</p> <p>35</p> <p>36</p> <p>37</p> <p>38</p> <p>39</p> <p>40</p> <p>41</p> <p>42</p> <p>43</p> <p>44</p> <p>45</p> <p>46</p> <p>47</p> <p>48</p> <p>49</p> <p>50</p> <p>51</p> <p>52</p> <p>53</p> <p>54</p> <p>55</p> <p>56</p> <p>57</p> <p>58</p> <p>59</p> <p>60</p>	<p>Page 10 Line 180</p> <p>We collected data via focus groups, interviews, and surveys in order to triangulate data. We also wanted to reach as many community members as possible so we engaged people online, at the offices of the nonprofit organization, and at community health fairs.</p>

1		
2	Data collection instruments and technologies - Description of instruments (e.g.,	
3	interview guides, questionnaires) and devices (e.g., audio recorders) used for data	
4	collection; if/how the instrument(s) changed over the course of the study	
5		
6	Units of study - Number and relevant characteristics of participants, documents,	
7	or events included in the study; level of participation (could be reported in results)	
8		
9	Data processing - Methods for processing data prior to and during analysis,	
10	including transcription, data entry, data management and security, verification of	
11	data integrity, data coding, and anonymization/de-identification of excerpts	
12		
13	Data analysis - Process by which inferences, themes, etc., were identified and	
14	developed, including the researchers involved in data analysis; usually references a	
15	specific paradigm or approach; rationale**	
16		
17	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness	
18	and credibility of data analysis (e.g., member checking, audit trail, triangulation);	
19	rationale**	
20		

Results/findings

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23	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and	
24	themes); might include development of a theory or model, or integration with	
25	prior research or theory	
26		
27	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts,	
28	photographs) to substantiate analytic findings	
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Discussion

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32	Integration with prior work, implications, transferability, and contribution(s) to	
33	the field - Short summary of main findings; explanation of how findings and	
34	conclusions connect to, support, elaborate on, or challenge conclusions of earlier	
35	scholarship; discussion of scope of application/generalizability; identification of	
36	unique contribution(s) to scholarship in a discipline or field	
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38	Limitations - Trustworthiness and limitations of findings	
39		

Other

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42	Conflicts of interest - Potential sources of influence or perceived influence on	
43	study conduct and conclusions; how these were managed	
44		
45	Funding - Sources of funding and other support; role of funders in data collection,	
46	interpretation, and reporting	
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*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: 10.1097/ACM.0000000000000388

For peer review only

BMJ Open

Development of a Cultural and Linguistically Sensitive Virtual Reality Educational Platform to Improve Vaccine Acceptance within a Refugee Population: The SHIFA Community Engagement-Public Health Innovation Program

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-051184.R1
Article Type:	Original research
Date Submitted by the Author:	02-Jul-2021
Complete List of Authors:	Streuli, Samantha; University of California San Diego, Anthropology Ibrahim, Najla; Somali Family Service of San Diego Mohamed, Alia; San Diego State University Sharma, Manupriya; Palomar College Esmailian, Markie; Illumesense Inc. Sezan, Ibrahim; Distinct Insights LLC Farrell, Carrie; San Diego State University Sawyer, Mark; University of California San Diego School of Medicine Meyer, Dan; The University of Texas Southwestern Medical Center El-Maleh, Khaled; QUALCOMM Inc Thamman, Ritu; University of Pittsburgh Department of Medicine Marchetti, Alex; Miami University Lincoln, Alan; Alliant International University - San Diego Courchesne, Eric; University of California San Diego School of Medicine Sahid, Ahmed; Somali Family Service of San Diego Bhavnani, Sanjeev; Scripps Clinic La Jolla - Genesee Executive Plaza, Healthcare Innovation & Practice Transformation Laboratory
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Public health
Keywords:	Paediatric infectious disease & immunisation < PAEDIATRICS, QUALITATIVE RESEARCH, Community child health < PAEDIATRICS

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3 **Development of a Cultural and Linguistically Sensitive Virtual Reality Educational Platform to Improve**
4 **Vaccine Acceptance within a Refugee Population: The SHIFA Community Engagement-Public Health**
5 **Innovation Program**
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49 **Keywords:** vaccination, refugee health, community engagement, virtual reality, education
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51

52 20 **Manuscript Word Count:** 4502
53
54

55 **Figures and Tables:** 6
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Number of References: 23

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25 **ABSTRACT**

6 **Objectives:** To combat misinformation, engender trust, and increase health literacy, we developed a
7 culturally and linguistically appropriate virtual reality (VR) vaccination education platform using
8 community-engaged approaches within a Somali refugee community.

12 **Design:** Community based participatory research (CBPR) methods including focus group discussions,
13 interviews, and surveys were conducted with Somali community members and expert advisors to design
14 the educational content. Co-design approaches with community input were employed in a phased
15 approach to develop the VR storyline.

19 **Participants:** 60 adult Somali refugees and 7 expert advisors who specialize in healthcare, autism
20 research, technology development, and community engagement.

26 **Setting:** Somali refugees participated at the offices of a community-based organization, Somali Family
27 Service, in San Diego, California and online. Expert advisors responded to surveys virtually.

31 **Results:** We find that a CBPR approach can be effectively used for the co-design of a VR educational
32 program. Additionally, cultural and linguistic sensitivities can be incorporated within a VR educational
33 program and are essential factors for effective community engagement. Finally, effective VR utilization
34 requires flexibility so that it can be used among community members with varying levels of health and
35 technology literacy.

41 **Conclusion:** We describe using community co-design to create a culturally and linguistically sensitive VR
42 experience promoting vaccination within a refugee community. Our approach to VR development
43 incorporated community members at each step of the process. Our methodology is potentially
44 applicable to other populations where cultural sensitivities and language are common health education
45 barriers.

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List of Abbreviations:

CBPR: Community based participatory research

50 CHW: Community health worker

MMR: Measles, mumps, and rubella vaccination

SFS: Somali Family Service

VR: Virtual reality

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3 55 **ARTICLE SUMMARY**
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5 **Strengths and Limitations of this Study**
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- 7
- 8 ● This work shows that community based participatory research plays an important role in the
9 creation and customization of health interventions for underserved populations.
10
 - 11 ● The qualitative aspects of this study provide in-depth information that can help to address
12 complex vaccine hesitancy issues among Somali refugees.
13
14 60 ● Community-engagement methods such as community co-design are effective strategies that
15 employ the community itself for refugee health promotion and for new technology
16 development.
17
 - 18 ● We employed an iterative, phased approach to the development of educational content which
19 allowed us to continuously assess the project and how it impacted the refugee community.
20
21 65 ● This project is a pilot study with a small sample size which will need to be expanded to truly
22 understand the effect of our virtual reality health innovation on refugee vaccine perceptions and
23 behaviors.
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INTRODUCTION

Over 300,000 refugees enter the United States every year. While refugee resettlement has increased over time, events as recent as 2015 mark one of the largest exoduses of forced human migration, sparking a crisis as countries struggle to cope with the influx and the social and economic demands that coincide with human resettlement [1]. What is largely missing in the public discussion is an appreciation that refugees face extraordinary challenges throughout their migration process from origination to destination. One challenge in particular – the access to proper healthcare - is critical, both for those that have been resettled in the past and those who have recently arrived [2]. The other challenge is to collect and monitor healthcare data that can be accessed and disseminated to resettled communities for public health monitoring [3]. In recognition of these challenges, important questions range from how to efficiently meet the healthcare demands of a growing population that is effective and sustainable to providing an engagement that uses culturally specific resources that simultaneously enhances health education and drives an increased level of trust in the local healthcare system [4].

Upon resettlement in Western countries, many Somali refugees were faced with the widespread diagnosis of autism, a developmental disorder which was unfamiliar to them prior to migration [5]. On one hand, among a community cluster of resettled Somali children in Minneapolis, the prevalence of autism has exceeded 3% and has eclipsed the national average of 1.9% [6]. On the other hand, this specific refugee community was targeted by anti-vaccination activists and the propaganda that vaccination is a cause of autism. This misinformation led to concern by Somali parents and distrust in the healthcare system, which has resulted in a propensity for vaccine hesitancy and non-acceptance [5,6,7]. A lack of effective messaging towards what does cause autism and the dissemination of anti-vaccination propaganda were successful in decreasing vaccination rates in the Somali refugee population in Minnesota from 92% to 42% over the span of a decade [7,8].

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3 Effective healthcare education relies on various principles for building essential skills, including
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5 95 communication, assessing the accuracy of information, decision making, planning, goal setting, and self-
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7 management [9]. At its core, health education must be simple, retained, and must be assimilated within
8
9 those factors relevant to a given individuals biases and acceptances towards the delivered message [9].
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11 New digital innovations such as virtual reality (VR) has emerged as a tool to provide an enriching and
12
13 immersive learning experiences that promote understanding in acute conditions such as anxiety and post-
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15 traumatic stress disorder, and chronic conditions such as tobacco cessation,[10-12]. VR has also been used
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17 100 to provide patients with a more positive experience in hospital settings by using virtual nurses that
18
19 patients can relate to [13]. The ability for VR to increase information retention and to change health
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21 behaviors by engaging users in a non-healthcare environment makes VR a potentially valuable platform
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23 for visual health education. Therefore, our primary aim was to develop a customized, culturally and
24
25 linguistically appropriate VR educational program specifically focused on pediatric vaccinations, and to
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27 105 leverage community based participatory research models and community co-designs to build, test, and
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29 deploy VR at the community level among a group that are known to be vaccine hesitant or vaccine
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31 resistant.
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39 110 **METHODS: STUDY DESIGN**

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41 SHIFA (Arabic for 'healing') is a community innovation program to design, deploy, and utilize new
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43 healthcare innovations with an inclusive model of community engagement. Within the current program,
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45 community based participation was incorporated along three complementary approaches [14]. These
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47 include:
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51 115 1) To define the health care access barriers in a resettled refugee community with a focus on
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53 pediatric vaccination.
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55 2) Incorporate a community-based participatory model to develop the virtual reality content
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3 with community member co-design.
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- 5 3) Develop a virtual reality environment that is customized with cultural, linguistic, and religious
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7 sensitivities to provide appropriate health education.
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10 Qualitative feedback was derived through focus group discussions, interviews, and surveys developed by
11 the investigators and was completed by community members and experts for analysis during each phase
12 of technology development. Focus groups and interviews were conducted by Najla Ibrahim and Samantha
13 Streuli. Najla Ibrahim is a Somali woman who holds an MPH degree and is an expert in community public
14 health issues. Samantha Streuli is a white woman who holds a PhD in anthropology and who has been
15 working with the Somali community for three years. The majority of focus group and interview
16 participants were unknown to Samantha and Najla prior to the research project, though some were
17 acquaintances from previous work within the Somali community.
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30 130 ***Ethics Approval Statement***

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32 This study was approved by The University of California San Diego Institutional Review Board (Protocol
33 #171434).
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39 ***Patient and Public Involvement***

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41 135 The Somali community was involved in the research from its inception and were regularly consulted as
42 the research was developed. Focus groups and interviews with the community informed the development
43 of research questions, which prioritized the experiences and interests of the Somali community. We
44 consulted with community members and community leaders when designing and conducting the study
45 and developing survey, focus group discussion, and interview questions to determine outcome measures.
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52 140 Somali community members were also involved in the recruitment to the study, as much of the
53 recruitment happened via word-of-mouth. The results of the study will be presented to participants and
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3 other community members, who will be further consulted via focus groups on how to best disseminate
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5 results.
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10 145 **Participants**

11 *Inclusion/Exclusion Criteria*

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13 We identified groups of Somali individuals for community participation and VR co-design. Participants
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15 were required to be members of the Somali community in San Diego, California who were over the age of
16
17 18 and were either 1) Somali refugees; 2) Somali immigrants; or, 3) US-born Somali Americans. We
18
19 18 and were either 1) Somali refugees; 2) Somali immigrants; or, 3) US-born Somali Americans. We
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21 150 selected a group of 7 expert advisors to assist in the development of VR. These advisors included: 1)
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23 researchers or other experts in autism and/or vaccination; 2) physicians serving the San Diego Somali
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25 community and in pediatric health; 3) leaders within the Somali community.
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30 **Setting**

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32 155 San Diego County is the 3rd largest metropolitan area in California and the 12th largest resettlement area
33
34 in the United States. The organization responsible for the development and execution of the program is
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36 Somali Family Services (SFS), a fiscal sponsor for the East African Collaborative of 8-community
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38 organizations that aims to outreach, educate, and enroll refugees and immigrants in health insurance
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40 programs. This specific community predominantly resides in City Heights, a subdivision of San Diego
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42 160 County that has a population of 75,000 individuals. Socioeconomic statistics of this region includes a
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44 median household income of \$39,330 (national median \$55,322), 40% are immigrants and/or refugees,
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46 with 31% having an education level of a bachelor's degree or greater [15].
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51 **Recruitment**

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53 Somali individuals were recruited via telephone and through word-of-mouth by Somali Community Health
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55 Workers (CHWs) and peers. As a non-interventional and non-comparative program, we did not determine
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3 an a priori sample size and identified consecutive participants interested in participating within the
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5 community engagement design. As such, we included any individuals without a predefined minimum or
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7 maximum sample size. In total, we included 60 community participants and 7 expert advisors. Our target
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9 participants were: a) parents of children between 0-2 years of age, b) pregnant, or c) planning to become
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11 pregnant in the next two years; however, we included those Somali community members interested in
12 170 pregnant in the next two years; however, we included those Somali community members interested in
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14 issues of autism and/or vaccination regardless of parental status. All participants consented to have their
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16 names and contact information collected for future correspondences. This information was securely
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18 stored in an encrypted file and only used to re-contact participants who agree to be re-contacted. The
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20 research objectives, research participants' rights, and description of how data would be used were
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22 explained to all participants prior to participation. All participants provided verbal consent, which was
23 175 explained to all participants prior to participation. All participants provided verbal consent, which was
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25 approved by The University of California San Diego Institutional Review Board (#171434).
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30 Expert advisors were identified by the SHIFA project leadership team according to their particular areas
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32 of specialization. Advisors signed consent forms to participate in the iterative development of educational
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34 180 content.
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39 ***CBPR and Community Co-Design***

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42 Our CBPR approach involved community members in each step in the design, iterative testing, and
43
44 development of culturally and linguistically appropriate health education content. This approach to CBPR
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46 185 in the Somali community builds upon public health work previously done within refugee communities
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48 [16]. We developed a community co-design methodology that uses the principles of design thinking
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50 combined with community-based research to enable participants to be directly involved in the design and
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52 creation of content and products that are developed to benefit them [16-17]. This co-design methodology
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3 was inclusive in that community members were asked to participate within content curation and to lead
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5 190 certain aspects of VR development.
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7 ***Phased Approach to Virtual Reality Development***

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10 We merged each aspect of CBPR and community co-designs within a phased approach to VR development
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12 (Vendor: INVIVO, Toronto, Canada). These phases included:
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14

15 **Phase 1:** CBPR approaches to assess community needs and concerns important to pediatric vaccination.
16

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18 195 **Phase 2:** VR modality determination for script development. The modality consisted of the type of VR
19
20 experience and the script development included the specific educational content.
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23 **Phase 3:** VR Prototype and iterative feedback from storyboards, 2- and 3-dimensional animation, and
24
25 visual and audio experiences that incorporate VR design elements including those factors that allow users
26
27 to engage at different levels of health literacy.
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31 200 **Phase 4:** Final VR Product and Testing
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34 The objective within VR development was to use those tools and devices that were available to the
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36 community-at-large and to ensure cultural and linguistic sensitivities were incorporated.
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42 ***Data Collection and Analysis***

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45 205 All data were collected electronically via tablet or computer at the time of focus group discussions,
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47 interviews, and surveys. Focus group discussions and interviews were either recorded and transcribed, or
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49 extensive notes were taken on a computer in the event that groups or individuals declined to be recorded.
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51 Focus group discussions took place at the offices of SFS. In total, we conducted 5 focus groups with 57
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53 participants. Some participants attended more than one focus group. Four of the focus groups were
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3 210 structured (see supplementary materials for discussion guides), while one was an unstructured discussion
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5 of the prototype. Interviews also took place at the offices of SFS and were conducted with 3 Somali
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7 parents. While the majority of participants were female, we also had a small number of male participants.
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10 Analyses were conducted thematically and iteratively using the content of the surveys, focus group
11
12 discussions, and interviews during the phased approach for VR development. This approach utilized five
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14 215 steps: 1) familiarization, 2) coding, 3) theme development, 4) defining themes and, 5) reporting [18].
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17 During the process of familiarization, all sections of the interviews, focus group discussions, and surveys
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19 relating to the experience of utilizing VR were extracted. Coding was performed using MAXQDA software.
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21 Emergent themes from each phase of development were defined and reported in order to inform the
22
23 subsequent development phases.
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27 220 The primary data coder was SAS. To ensure a rigorous evaluation of the data, a subset of transcripts was
28
29 also coded by AM. In order to achieve consensus on codes, AM and SAS engaged in recurring discussions
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31 on the coding process. The analysis was further tested during discussions with expert advisors. The
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33 consensus was reviewed and approved by all investigators. Specific quotations were chosen by SAS to
34
35 represent emergent themes in the data.
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39 40 **RESULTS**

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42 This program began in April 2019 and product testing is ongoing. Figure 1 illustrates the phased approach
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44 to development and iterative testing. In total, 67 individuals (7 advisors, 60 Somali community members)
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46 provided feedback during each phase of VR development and participated within the community-co
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48 230 design.
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Community-based Participation

235 The first step in our community engagement process was to hold a series of 3 focus groups exploring
topics of interest to the Somali community including vaccination, autism, pediatric health, and technology
(n = 18 Somali community members). We also conducted interviews with 3 Somali parents (see
supplementary files for interview guide). Based on this initial feedback from the community, the project
team held a design workshop to create a series of 3 story ideas for the VR. These ideas were then brought
240 to the Somali community in the form of another design workshop where the community evaluated the
suitability of the provided stories and suggested changes. 4 Somali community members (2 Somali
community health workers, 1 Somali woman, and 1 Somali man) participated in this design workshop to
develop the general framework of a story. Information learned from the community was then used to
develop a first iteration of a script. This script was then tested for cultural and linguistic suitability and
245 vaccine-promotion potential with 17 Somali women from ages 26-78 and was followed by a discussion
with a prominent male community leader to again assess the cultural and linguistic appropriateness of
the content to promote vaccine education. Finally, a 2-dimensional prototype of the VR animation was
developed with a Somali voiceover (Figure 2) and was tested with 24 community members in order to
determine the effectiveness of the messaging in promoting vaccination and to assess cultural and
250 linguistic elements of the storyline.

Phased Approach to Virtual Reality Technology Development

Phase 1: CBPR approaches to assess community needs and concerns important to pediatric vaccination

The Somali community focus group discussions were broken up into three separate sessions, each of
255 which focused on a particular area of community interest (Table 1). The first focus group discussion was

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2
3 centered on health concerns of the community, and participants cited autism as a major concern, as
4 well as language barriers that pose a significant problem when engaging with the medical system. In
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6 addition, participants brought up issues of trust which were tied to poor communication.
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12 260 The second focus group discussion explored issues of pediatric health. Participants provided information
13 about pregnancy, childbirth, pediatric care, and parenting. The central theme of this focus group
14 discussion was issues of trust within the medical system, with many mothers indicating that while they
15 highly valued their doctors' opinions, they also preferred to do their own research. Mothers relayed to
16 us their desire to receive health education in their own language from a trustworthy doctor.
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25 The third focus group discussion was centered around issues of vaccination and technology. Participants
26 once again indicated issues surrounding trust in medical systems and their desire to make their own
27 educated health decisions. Additionally, participants stated that they would like to receive more
28 detailed information about how vaccinations work:
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36 "If they could show how the vaccine works in the child's body and what it does – if it can be
37 visualized."
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43 "That before the vaccines are given to our children, for it to be explained to us what the risks are
44 - the sided effects, and the benefits. When we compare the two, then make a decision."
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50 Themes that emerged from interviews with 3 Somali parents also included concerns about autism,
51 medical trust, and the desire to learn more about vaccination.
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5**Phase 2:** VR modality determination for script development6
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Modality determination: The project team consulted extensively with Somali CHWs to determine an appropriate modality, and chose 360-video due to the ability of this format to be experienced using virtual reality headsets, smart phones, or computers in order to make this VR program widely accessible to all members of the Somali community.

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Script development: Open-ended survey responses from Somali community members regarding the three potential storylines indicated that an older Somali male doctor would be most suitable to deliver health information in our story, as this character would evoke feelings of trust and respect. Somali community members favored a scene where a Somali mother could be shown talking to her doctor – this way they could see themselves as a character in the VR story and could see their questions and concerns being addressed directly. The open-ended survey responses from community advisors indicated a preference for a storyline with a strong focus on family and supported the story concept of a Somali mother asking questions to a trusted physician. This information was used to develop the initial script.

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Six members of the expert advisory board reviewed the initial script. Advisors were asked to answer a series of six open-ended questions and provided insightful answers that assisted with script development (Table 2). Specifically, when advisors were asked for their overall impressions of the story, they stated:

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“Overall, I like how the story flows and the way in which the educational components are presented.”

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5 "I like the simplicity of the conversation with its effective focus on the key messaging of the
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8 305 value of the timely vaccination to help raise healthy kids."

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12 We conducted a community focus group discussion during the script review process to engage the
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14 community. Seventeen community members were asked to assess how culturally appropriate the
15
16 storyline was, what they would like to change, how impactful the story was, and how they would
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18 personally design the content. During this focus group discussion, participants agreed that the story was
19 310 clear and easy-to-follow; however, as additional questions were asked about story flow, the feedback
20
21 turned to autism. We found that even when we did not mention autism, the false association between
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23 autism and the measles, mumps, and rubella vaccine (MMR) came up as a topic of discussion. Many
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25 community members said that they were concerned about autism and the MMR vaccination. One
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30 315 woman asked:

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32 "if MMR doesn't cause autism, why did I see my child stop talking immediately after getting the
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34 MMR?"
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39 The participants agreed that the VR must address the autism question, and that they would prefer to
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41 320 learn this information from a doctor character in the VR storyline.
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46 Community members were also asked to take a brief survey after reviewing the script. This survey
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48 included questions about attitudes toward vaccination as well as vaccination planning. Notably, there
49
50 was an 18% increase in participants who endorsed being "very comfortable" with MMR vaccination
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52 325 following script exposure. Additionally, those who said they were "not at all comfortable" with MMR
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3 vaccination decreased by 12% following script exposure. There was also a 17% increase in those who
4 stated they would allow their child to receive the MMR following script exposure (Table 3).
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7 **Phase 3: VR Prototype and iterative feedback**

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10 Three expert advisors provided feedback on the storyboard and prototype that focused on where
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12 330 characters were positioned (i.e. husband next to wife), color scheme, and highlighted the need to describe
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14 the immune system's function in order to retain scientific accuracy in the communication of vaccination
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16 information.
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22 The prototype (Figure 2) was tested with the Somali community in the context of an in-person focus group
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24 335 discussion and surveys that took place in person at the SFS offices. Participants in the focus group
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26 discussion were asked a series of open-ended questions about their experience with the prototype. The
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28 primary focus of this discussion was analysis of the storyboards and stylistic elements of the VR experience
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30 (e.g., color preferences, imagery, portrayal of characters). Participants indicated that they highly valued
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32 the Somali voiceover and preferred to include the discussion of autism in the final VR storyline, as its
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34 exclusion would raise more questions for the community. The participants also felt that the father
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36 340 character in the VR storyline seemed somewhat excluded and should be standing near his wife to signal
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38 support.
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43 All participants who reviewed the prototype agreed that the inclusion of culturally appropriate characters
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45 and a Somali voiceover maximized the educational experience. 13/24 (54%) participants stated that the
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47 345 prototype made them either more comfortable or much more comfortable with vaccination than they
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49 were before exposure to the prototype. 20/24 (83%) participants stated that they would recommend
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51 MMR vaccination to members of their community following exposure to the prototype. Additionally,
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53 21/24 (88%) said they planned to vaccinate their children following exposure to the prototype.
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6 350 *VR design factors:* The key VR design elements that were incorporated within each phase of VR
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8 development include passive, non-intrusive experiences, a dynamic and interactive visualization, and
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10 prompts that promote the user towards self-reflection.
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16 **Phase 4: Final Product and Testing**

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19 355 The final product is a four minute 360-video animation (<https://youtu.be/NS8GvtxnIk0>) available in Somali
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21 and English languages. It can be viewed online using a tablet, a smart phone, or with VR goggles. Settings
22
23 include a Somali home populated by a family, and a doctors' office. In the animation's introduction, we
24
25 meet the expectant mother who states that she is expecting her first child and is trying to make decisions
26
27 about vaccination. Figure 3 illustrates in screenshots each of the 4 chapters in the VR experience. We plan
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30 360 to test the final product using an A/B testing model with the Somali community wherein the A group
31
32 receives the VR education and the B group receives a basic English-language educational video about
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34 vaccination. Both groups will be surveyed before and after exposure to the educational materials to assess
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36 changes in attitude toward vaccination and willingness to vaccinate.
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43 365 **DISCUSSION**

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46 The main results of the SHIFA program can be summarized as follows: 1) a community
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48 participatory research model can be effectively translated for the co-design of a VR educational program
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50 with community members involved in each phase of technology development; 2) cultural and linguistic
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52 sensitivities can be incorporated within a VR pediatric immunization educational program and are
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54 essential factors for effective community engagement; and 3) effective VR utilization requires flexibility
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3 that can be used among community members with varying levels of health and technology literacy. To
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5 the best of our knowledge, our VR development is the first such health innovation for vaccination
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7 education designed by a community of refugees known for vaccine hesitancy.
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13 **375 *Refugee Learners – Vaccination & Autism***

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16 This community has common barriers to effective education such as a lack of information and
17
18 information that is not culturally and/or linguistically appropriate to drive understanding [19]. Regarding
19
20 immunizations, many parents and caregivers in this community already possess medically inaccurate
21
22 information. We have previously determined that within this refugee community the reason not to
23
24 immunize has resulted from misinformation and the perception that vaccination results in autism.
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27 Although MMR vaccination rates have fallen in the Somali community (from 92% to 42% over the span of
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29 a decade [7,8]) rates of autism and pediatric learning impairments have remained high (1:32 Somali
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31 children have autism compared to the national average of 1:54) [20-21]. While these results do not
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33 support the link between vaccination and autism, many parents are still convinced of an association
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36 **385** between MMR and autism. Given these results, it is important to take into consideration the mental and
37
38 emotional state and the ideation that arises from associating vaccinations with autism. Within this
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40 community health engagement related to immunization requires education focused on the importance
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42 of vaccinations for newly arrived refugees, and a re-education among those who have previously elected
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44 not to immunize. In this context, we performed a community health assessment and identified the drivers
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47 **390** for a low rate of vaccination in the Somali community ranging from cultural and language barriers, distrust
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49 in the healthcare system, and the misinformation that vaccination results in autism. Recognizing these
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51 drivers for low immunization rates in this community, our observations for the mechanisms for how VR
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53 affects behavior changes include: content that is culturally relevant, stimulates an awareness and
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3 expectation for what vaccines do and do not do, and provides an immersive experience leading to
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5 395 information retention [22].
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10 11 ***VR CBPR and Co-Designs*** 12

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14 In addition to the mechanisms for how VR affects behavioral change, several design factors must
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16 be maintained when considering who interacts with the VR technology and especially among immigrants
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18 400 that may have varying levels of health and digital literacy. Within our program, most community members
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20 experienced a positive interaction with VR. There are several plausible reasons for our observations.
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22 Through community co-designs, we leveraged key design factors including a non-intrusive experience
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24 (users learn in their own environment), a passive interaction (content that is visual, audio, and depicted
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26 versus reading), a dynamic storyline that builds upon previous experiences and uses known environments,
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29 405 and promotes self-reflection by allowing the user to introspect and contemplate during the VR experience.
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34 Because we recognized the importance of culturally and linguistically appropriate educational
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36 materials to deal with issues of low health literacy and medical distrust, we included community-based
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38 approaches in each phase of our development. The results of focus groups and surveys conducted within
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41 410 the community revealed several important considerations for the development of our VR storyline. For
42
43 instance, community members were much more comfortable receiving information from a trusted doctor
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45 character. Community members also felt it necessary to include direct and clear information about the
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47 lack of relationship between autism and vaccination in our storyline. This was in contrast to our
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49 expectation and that doing so would reinforce this misinformation. Following design workshops with the
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52 415 Somali community, we tested the program that they helped to co-design within the community in order
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54 to address its cultural and linguistic appropriateness as well as its ability to promote vaccination behavior.
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3 We also tested the VR storyline with a team of subject matter experts who evaluated the scientific
4 accuracy and usability of our design. In our community testing, we found that many Somali community
5 members felt the VR storyline engendered trust, was relatable, was educational, and was convincing.
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10 420 Several focus group and survey participants stated that they planned to vaccinate and to recommend
11 vaccination to others following exposure to the VR. Our testing with our panel of experts found that our
12 content was user-friendly, easy to understand, and scientifically accurate.
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17 While we appreciate that community co-designs are an important methodology for how a new
18 technology is designed, a foundation of CBPR is necessary to harness community involvement. To employ
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21 425 CBPR, we engaged community members throughout every step of the process. Before developing the idea
22 for the VR storyline, we engaged the community in a series of three focus groups to better understand
23 their needs, strengths, and interest in collaboration. Focus group discussion questions were open-ended
24 and allowed for participants to bring their interests and concerns into the conversation. Information
25 learned from these engagements was used to begin to develop the culturally and linguistically appropriate
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32 430 storyline for the VR. Community members were also continuously engaged throughout the development
33 of the VR storyline through community co-design.
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40 It is our plan to leverage the educational curriculum as well in future deployments of VR. Due to
41 the constraints of COVID-19, we are currently exploring the possibilities of using telehealth and other
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44 435 digital communication platforms to safely and effectively deploy the VR into the community. Addressing
45 vaccine hesitancy is especially relevant within the context of COVID-19, as vaccination rates for
46 preventable diseases have dropped significantly since the beginning of the COVID-19 crisis [23]. There are
47 also concerns about the potential of misinformation related to COVID-19 vaccination that is especially
48 relevant for an underserved community that is largely excluded from vaccine clinical trials and
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55 440 communities that have a history of vaccine hesitancy.
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Limitations

Our community feedback and focus group represents a convenience sample for those that are more apt towards vaccine acceptance, and therefore may not completely capture all concerns among those who are vaccine hesitant. While this represents a potential selection bias, our method to include a wide range of community members as well as internal and external advisors may enhance internal validity by incorporating a heterogeneous group for community input. Community based participation and community co-designs at each stage of VR development from the initial idea through completion of a VR animation may enhance external validation by including the key components related to cultural and linguistic sensitivities within the phased approach for VR development. COVID-19 impacted our abilities to recruit more participants and to test our final VR experience within the community in the way that we had initially planned to. We are attempting to mitigate this limitation by administering online surveys in the Somali community after they view the VR at home; however, this may limit the quality of our data as most individuals do not have VR headsets at home and may not get the full immersive effect without them. Finally, a perceived shift from vaccine hesitancy to vaccine acceptance at this point is subjective and requires real-world validation and prospective follow-up confirming vaccine delivery.

CONCLUSION

We employed community-based participatory approaches, and community co-design to develop an innovative vaccine educational technology with Somali refugees using VR. By combining new technology-enabled approaches with the needs, interests, and expertise of Somali community members, we have created a methodology that can address vaccination beliefs and behaviors in a vaccine hesitant refugee population. Future research will include an assessment of the efficacy of the VR platform on

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3 vaccination rates over time, as well as continued community engagement for the development of
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5 465 additional VR content which can increase health literacy within underserved populations.
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10 11 **ACKNOWLEDGEMENTS** 12 13

14 We first extend our sincerest gratitude to the Somali community for their inspiring engagement in this
15
16 project. Next, we would like to thank Fadumo Jama, Ahmed Dahir, and Sahra Nor for their assistance with
17
18 470 participant recruitment, facilitation of community engagements, and translation and interpretation
19
20 services. Finally, we are grateful to Dr. Ahmad Bailony and Karen Henken for their guidance and input on
21
22 this project.
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29 **CONTRIBUTORSHIP STATEMENT** 30 31

32 475 SS, NI, and AM contributed to the collection and analysis of data for this work. SS and SB contributed to
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34 the initial drafting of the manuscript. SS, NI, MS, ME, IS, MSa, AS, and SB contributed to the conception
35
36 and design of the work. All authors (SS, NI, AM, MS, ME, IS, CF, MSa, DM, KE-M, RT, AM, AL, EC, AS, and
37
38 SB) contributed to the interpretation of the data, revising the work critically for important intellectual
39
40 content, providing final approval of the version to be published, and all agree to be accountable for all
41
42 480 aspects for the work in ensuring that questions related to the accuracy or integrity of any part of the work
43
44 are appropriately investigated and resolved. The funders had no role in the design and conduct of the
45
46 study; collection, management, analysis, and interpretation of the data; preparation, review, or approval
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48 of the manuscript; and decision to submit the manuscript for publication.
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COMPETING INTERESTS

Carrie Farrell was a paid consultant on the project from inception until August of 2019. Alex Marchetti is a former employee of technology partner INVIVO and her engagement with the project began while she was with that organization in 2018. Sanjeev Bhavnani discloses Scripps Clinic Grants for clinical trials related to machine learning and technology designs in cardiovascular imaging, being a Pfizer Health Information Technology Advisory Board member on strategies related to health information technology, being a Bristol Meyers Squibb Digital Health Advisory board member on strategies related to digital health technologies, being an Anthem AI Consultant on projects related to cardiovascular care, being a Proteus Health Chair DSMB on digital medication monitoring in hepatitis C, being an American College of Cardiology Innovations Advisory Group Principal investigator and committee member on various innovation projects in cardiovascular care, having Analytics4Life Stock options as a scientific advisor on artificial intelligence in cardiovascular diagnostics, and having Blumio Stock options as a scientific advisor on new technology designs in hypertension. Markie Esmailian discloses US patents in Illumesense Inc., using data analytics and machine learning algorithms for clinical decision support for alternative health therapies. Markie Esmailian is also Founder of IllumeSense Inc. as majority shareholder and principle. Ahmed Sahid, Najla Ibrahim, and Samantha Streuli were all paid employees of Somali Family Service at the time of this research. Alia Mohamed was also a paid research assistant for this project. All other authors declare that they have no relevant or material financial interests that relate to the research described in this paper.

FUNDING

Alliance Healthcare Foundation Grant #18-34728477.

DATA SHARING STATEMENT

510 Data are deidentified participant data and are available from the corresponding author upon request.

Reuse is not permitted.

For peer review only

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TABLE 2. Questions and Responses from Project Advisors

Questions Asked to Advisors	Salient Responses
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TABLES

TABLE 1. Focus Group Questions and Responses from Somali Community

Category and Questions for Community Members	Salient Responses
Session 1: General Health	
Examples of questions asked in focus groups	
“What are some of your community’s biggest health concerns in the U.S.?”	“Autism.” “One of the biggest health problems that people have that I forgot to mention is that most people don't understand a lot of English.”
“What do you find not trustworthy within the health care system?”	“Lack of good communication...especially in primary language.” “Health insurance!”
Session 2: Pediatric Health	
Examples of Questions asked in focus groups	
“Do you trust your doctor’s recommendations for your child’s health?”	“Yes, whatever recommendation the doctor gives me, I have to take it.” “I mean I always think it's obviously for a good reason, but for me, I think I always do my own research before I automatically assume that's what's best for me. If it's something very serious like [the doctor] saying for example 'you need a surgery,' that [I] automatically would be like 'let me get another opinion from another doctor.’”
Session 3: Vaccination	
Examples of questions asked in focus groups	
“What are the topics or things that you would like to know about in relation to vaccines?”	“If they could show how the vaccine works in the child’s body and what it does – if it can be visualized.” “That before the vaccines are given to our children, for it to be explained to us what the risks are - the sided effects, and the benefits. When we compare the two, then make a decision.”

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Table 1: Sample questions and salient responses from exploratory focus groups indicated that parents were very concerned about autism and that they found it difficult to trust the healthcare system due to lack of communication in their primary language. While parents trusted certain doctors, they also highlighted the importance of doing their own research to understand their children’s health. Parents also expressed a desire to understand how vaccines work within the body and what the risks and benefits are of vaccination.

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<p>1) What are your overall impressions of the story? What did you like the most about the story? Is there anything that you think should change in the story?</p>	<p>“Overall, I like how the story flows and the way in which the educational components are presented. I also think it’s a great idea to have the story centered around a meal, as it seems culturally relevant and helps make the situation relatable to users.”</p>
<p>2) Have you noticed any inaccuracies in scientific and medical facts in the story?</p>	<p>“Based on my past feedback, I am glad that this story has been selected. I like the simplicity of the conversation with its effective focus on the key messaging of the value of the timely vaccination to help raise healthy kids.”</p>
<p>3) Was the story clear and easy to understand? Did the story flow naturally?</p>	<p>“No.”</p> <p>“No, from my knowledge all of the content presented is accurate.”</p>
<p>4) Was the story culturally appropriate? Was the cultural component balanced throughout?</p>	<p>“Very clear and flowed in a way we would use in teaching in general. Very logical progression of information.”</p> <p>“Yes, the story is clear and flows very naturally.”</p>
<p>5) Was the story convincing? Does it have a potential to change attitudes of vaccine hesitant parents?</p>	<p>“One of the things I liked about this story is the emphasis of the great Somali family bond that can be pivotal in achieving the goals of this project to leverage the great trust Somali parents put on their relative and educated community members.”</p> <p>“Yes, the story was culturally relevant and appropriate.”</p>
<p>6) In your opinion, does the story increase knowledge?</p>	<p>“I think it gives the information about immunization, the science behind it, and does not focus on the controversies, which have not been supported by medical data.”</p> <p>“Yes. I would just make sure we really take advantage of VR when we show the visuals inside the body and how vaccine’s function within the immune system.”</p>
	<p>“Yes, it stays with the facts in a positive way, in a healthy environment with the families.”</p> <p>“It can, depending on the background of the parents and audience and their desire to benefit from such educational program.”</p>

Table 2: Sample questions and salient responses from engagement with project advisors. Advisors enjoyed the clarity and flow of the storyline as well as finding it culturally relevant and appropriate. They also believed that the story had significant potential to increase vaccine knowledge.

TABLE 3: Survey following initial script exposure

How comfortable are you with MMR vaccination?	%	How comfortable are you with MMR vaccination?	%	Would you get MMR for your child?	%	Would you get MMR for your child?	%
Very comfortable	52%	Very comfortable	70%+	Yes, I would	65%	Yes, I would	82%+
Somewhat comfortable	24%	Somewhat comfortable	18%-	I would consider it	23%	I would consider it	12%-
Not at all comfortable	24%	Not at all comfortable	12%-	I don't know	6%	I don't know	0%-
				No, I would not	6%	No, I would not	6%

Table 3: This table shows the results of a survey of 17 Somali mothers following exposure to the initial script for the VR. + indicates % increased following exposure to the script, - indicates % decreased following exposure to the script.

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FIGURES

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Figure 1: Phased approach to VR development. Assessment of community needs began in April 2019 in advance of the development of the VR. Iterative testing took place throughout 2019 and 2020, with some gaps in testing due to the restrictions of the COVID-19 pandemic. The final VR product has been completed as of June 2020 and is currently being tested with the Somali community.

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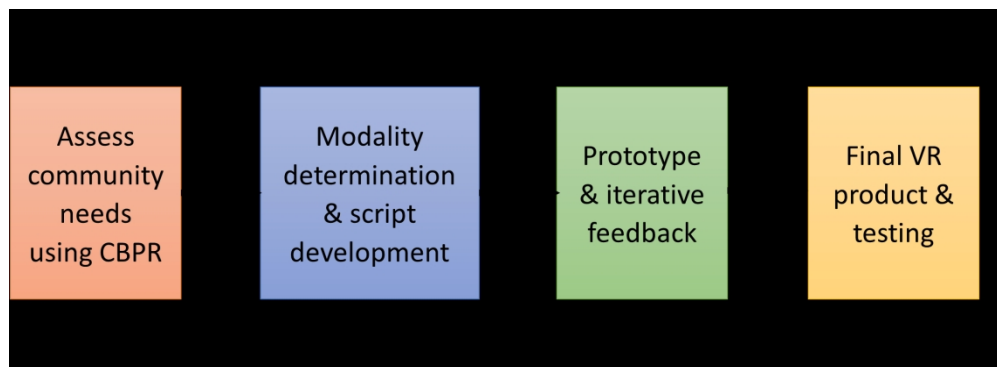
Figure 2: Still frame from prototype. The prototype consisted of a motion storyboard with a voiceover which was translated into Somali for presentation to the community.

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Figure 3: Top row: Chapters 1 and 2 of the VR story. Bottom row: Chapters 3 and 4 of the VR story. In chapter 1 of the animation, the expectant mother, her husband, and her sister visit the doctor's office and learn about measles, mumps, and rubella (MMR). In chapter 2, the family learns how the immune system works. In chapter 3, the family learns from the doctor what the MMR vaccine does and how it works. In Chapter 4, the doctor explains to the family the risks and benefits of MMR vaccination, including a statement debunking the association between autism and vaccination. Finally, the 360-degree video concludes by showing the new mother and her family – including the new, healthy baby – and the new mother states that after learning all the facts, she has decided to vaccinate her child.

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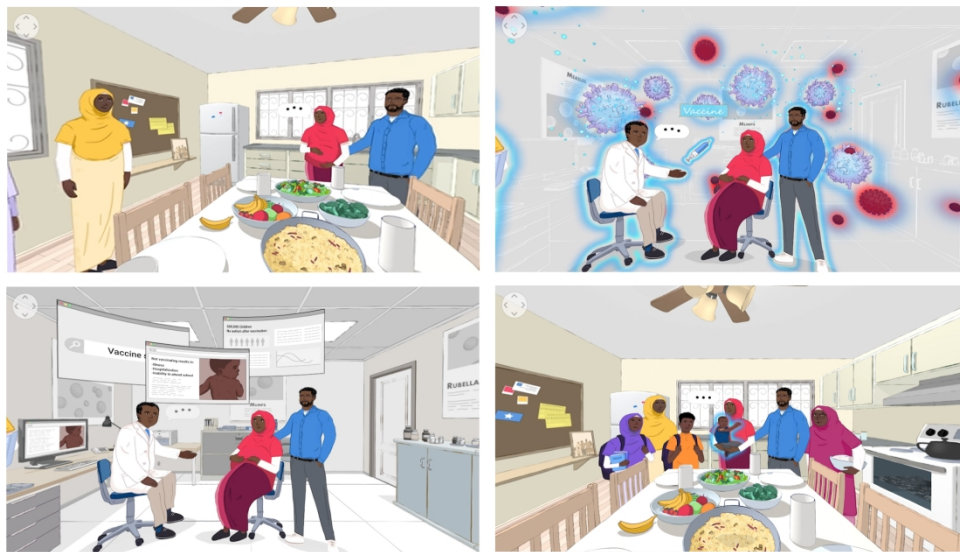


Phased approach to VR development. Assessment of community needs began in April 2019 in advance of the development of the VR. Iterative testing took place throughout 2019 and 2020, with some gaps in testing due to the restrictions of the COVID-19 pandemic. The final VR product has been completed as of June 2020 and is currently being tested with the Somali community.

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Still frame from prototype. The prototype consisted of a motion storyboard with a voiceover which was translated into Somali for presentation to the community.



Top row: Chapters 1 and 2 of the VR story. Bottom row: Chapters 3 and 4 of the VR story. In chapter 1 of the animation, the expectant mother, her husband, and her sister visit the doctor's office and learn about measles, mumps, and rubella (MMR). In chapter 2, the family learns how the immune system works. In chapter 3, the family learns from the doctor what the MMR vaccine does and how it works. In Chapter 4, the doctor explains to the family the risks and benefits of MMR vaccination, including a statement debunking the association between autism and vaccination. Finally, the 360-degree video concludes by showing the new mother and her family – including the new, healthy baby – and the new mother states that after learning all the facts, she has decided to vaccinate her child.

Focus Group 1 Discussion Guide

Questions about health in Somalia and refugee camps:

1. Q: What was your opinion of healthcare in Somalia?
2. Q: Did you receive health education (in Somalia)? What kind?
3. Q: If you spent time in a refugee camp, were you provided health services there?
4. Q: What kind of health services did you receive in Somalia (e.g. preventative, emergency, obstetric, etc.)?

Questions about resettlement process

1. Q: Were you provided with health services and/or screening as part of the resettlement process?
2. Q: Were you provided with health education as part of the resettlement process? What kind?
3. Q: If you have children, were you offered healthcare services for your children? What kind?

Questions about healthcare in the US

1. Q: What kinds of healthcare services have you received in the US (e.g. preventative, emergency, obstetric, etc.)?
2. Q: For what health conditions are you most likely to seek medical care?
3. Q: Where do you go for healthcare services?
4. Q: If you have children, what kind of healthcare services have they received?
5. Q: Have you received health education or information (in the US)? (From whom, about what?)
6. Q: What are some of your community's biggest health concerns in the US? Mental (or Autism)? Physical? Chronic Conditions?
7. Q: Who is the decision-maker in your household for health care?
8. Q: What sources of information do you use to make healthcare-related decisions? (e.g. family, friends, religious leaders, doctors, healthcare workers)
9. Q: Do you trust your healthcare provider and his/her guidance/recommendations?

10. Q: Is there any part/aspect of the healthcare system in the US that you do not find completely trustworthy?
11. Q: Who does your community (not just you) go to for healthcare? (who is trusted?) Are there specific hospitals people go to?

Focus Group 2 Discussion Guide

Introductory Questions

1. Do you have children (under 18 years old)? How many? What are their ages?

Prenatal Health Questions

1. If you've had children, did you experience your pregnancies here in the United States?
2. What is prenatal care? What do you know about prenatal care?
3. How do you feel about c-sections? (I ask because women seem to bring this up a lot and it is mentioned often in literature around Somali women's birth experiences in Western countries)
4. What did you learn through prenatal care that was valuable to your child rearing?
5. Where did you give birth? Where do mothers in your family or friends give birth?

Pediatric Health Questions

1. What do you know about pediatric (infant and childhood) health? Where do you get information about pediatric health (friends, family, internet, social media, doctors, etc.)?
2. How do you make decision about your child's healthcare?
3. Do What does the phrase "stages of development" mean to you? (If they're not sure we could explain and then ask the next part) What do you think the "stages of development" for children are? When do they happen?
4. Where do people learn about stages of development?
5. Who (or where) do your children go to see for healthcare?
6. When do you take your children to their doctor? How old are they typically? Yearly visits? How often? (routine preventive care, health and developmental guidance, screening for health conditions, treatment of acute and chronic conditions, and injury care)
7. What is a healthy child?

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8. What type of problems or challenges have you experienced with your own children when it comes to their health? What about in your community?
9. What barriers might prevent you from seeking or accessing healthcare for your children?
10. Do you have any advice or tips for young mothers and their young children when it comes to their healthcare?
11. If you were to watch educational video about pediatric health, how would you prefer to access or watch that?
12. How would you like to receive information about infant and child health in the future? (maybe give some options like using technology, watching videos, attending health fairs, attending workshops, formal classes, advice from doctors, etc.)
-

Focus Group 3 Discussion Guide

Questions about Vaccine Knowledge and Attitudes:

1. From your understanding, what are vaccinations for? What are their benefits? How do they work?
2. Do you understand how the vaccination works in your body?
3. Are vaccines effective against diseases/illnesses?
4. What information have you received about vaccinations and where?
5. Do you feel that the information you received was enough to make a good decision?
6. What information is missing that you would like to know about vaccination?
7. Do you feel like you get better information about vaccinations when you have a translator or someone like this present?
8. When did you first get vaccinated?
9. When did your children first get vaccinated? Why did you vaccinate them (i.e. school requirement)?
10. Why did you vaccinate (did school, doctors tell you?)
9. Why did you vaccinate in the US?
10. Where did you get vaccinated?

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3 11. If you were not told by a doctor or school to get vaccinated (prompted by someone else), would you
4 still vaccinate your children and why?
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7 12. As you might know, vaccines are conducted based on a schedule (based on age of child) – what are
8 your thoughts about the schedule? Frequency of the shots children are getting?
9
10 13. What do you think about frequency, amount, timing of shots?
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12 14. Have you heard of parents delaying vaccinations for their children?
13

14 **Questions about Anti-Vaccination:**

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17 15. Have you heard the recent news about disease outbreaks in the US caused by unvaccinated
18 children?
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20 16. If so, where did you hear that information? What are your thoughts about that?
21
22 17. What are reasons people decline vaccinations?
23
24 18. Are vaccines related to or a cause of any illness (besides autism)?
25
26 19. Do you know others in the community who are hesitant about vaccinations?
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29 **Questions about Technology:**

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31 20. If we were to create something educational for you and your community, what would be the best
32 way to teach?
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34 21. If you were to design the VR program what would you do or show?
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36 22. What kinds of experiences would you like to see? How vaccines work? Simulated interaction with
37 healthcare provider?
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44 **Script Review Focus Group Discussion Guide**

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46 1) What were your overall impressions of the script?
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48 2) Does the script have the potential to impact your community's beliefs about autism and vaccination?
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50 3) What did you like about the script?
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52 4) What would you change about the script?
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54 5) Is there anyone or anything that you think is missing from the script?
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-

Parent Interview Guide

Introductory Questions:

1. How old are you?
2. Do you have children? How many children do you have?
3. Are you married?
4. How long have you been in the US?

Interview Questions:

1. Where or who do you generally get your medical information from? Why?
2. What is autism?
3. From your understanding, what causes autism?
4. Do you know anyone in your community who has autism?

If their child:

1. Were you familiar with autism prior to your child's diagnosis?
 2. What signs or behaviors have caused you to seek medical help for your child?
 3. Can you explain the process of receiving an autism diagnosis for your child?
 4. What challenges have you faced as a parent of an autistic child?
 5. What challenges has your child faced as a child with autism?
 6. What treatments have you used to manage your child's autism?
5. How do people in your community view or understand autism?
 6. Is there anything you would like to know or understand about autism?
 7. How do you feel about vaccinations?
 8. Would you, or have you, vaccinated your children? Why did you make that choice?
 - Have you been made aware that vaccination and immunization records are now required for children to attend school in San Diego? How do you feel about that?
 9. How do you think other members of your community feel about vaccination?
 - What concerns or fears do other members of your community may have about vaccination?

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4 10. Do you know anyone in the Somali community in San Diego who has chosen not to vaccinate?
5 Why? Do you think they would be willing to speak with us?
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8 11. Do you feel like you've been provided enough information about vaccinations to make an
9 informed decision?
- 10 • Do you feel like members of your community are provided with enough information
11 about vaccination to make an informed decision?
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- 13 12. If you've changed your mind about vaccinations at any point, do you recall what that deciding
14 factor was? If you haven't changed your mind (or if you are still anti-vaccination or hesitant),
15 what may change your mind?
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- 18 13. What would you like to know or understand about vaccinations?
- 19 • What do you think members of your community would like to know or understand
20 about vaccinations?
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- 22 14. What do you know about Virtual Reality? Have you ever used it?
- 23 • Would you feel comfortable using VR for an education program? Do you think
24 members of your community would be comfortable using VR?
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 - 26 • Do you have any questions about Virtual Reality?
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29 15. What other formats would be best for developing a health education program for your
30 community? (video, game, lecture, workshop, discussion)?
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- 33 16. Is there anything else you think we should know or consider?
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35 0. Any questions for me?
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Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 3

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Page 6
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	Page 7 Line 102

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale**</p>	<p>Page 8 line 120</p> <p>Page 9 line 160</p> <p>We employed CBPR and community co-design in order to develop educational content that was created by and for the communities for whom it was intended. We used focus groups, interviews, and surveys in order to triangulate our data and to include the voices of the community in as many ways as possible.</p>
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Page 8 Line 121
<p>Context - Setting/site and salient contextual</p>	Page 8 Line 135

factors; rationale**	
<p>1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20</p> <p>Sampling strategy - How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale**</p>	<p>Page 8 line 125.</p> <p>Somali community members were chosen in the manner that they were because we recognize the importance of including the entire community in research. There is a strong oral tradition in Somali culture and parents often ask advice from extended family and community when making decisions about healthcare. Thus, we found it necessary to engage individuals of all ages and genders who spoke English and Somali to guide the educational material and provide their input.</p> <p>Expert advisors were chosen in order to provide us with another view of the issue from a technical angle so that we could better create something that could be realistically delivered to the community.</p>
<p>21 22 23 24 25 26 27</p> <p>Ethical issues pertaining to human subjects - Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues</p>	<p>Page 9 Line 150</p>
<p>28 29 30 31 32 33 34 35 36</p> <p>Data collection methods - Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale**</p>	<p>Page 10 Line 180</p> <p>We collected data via focus groups, interviews, and surveys in order to triangulate data. We also wanted to reach as many community members as possible so we engaged people online, at the offices of the nonprofit organization, and at community health fairs.</p>

1 2 3 4 5 6 7 8 9	Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Interview and focus group discussion guides were included as supplementary files. Types of questions asked are also described throughout the manuscript.
10 11 12 13 14 15 16 17	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Number of participants is described throughout the paper at each relevant event (n of focus group participants etc.)
18 19 20 21	Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Line 206
22 23 24 25	Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Line 213
26 27 28 29	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Line 221

Results/findings

31 32 33 34 35	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Described beginning on line 226.
36 37 38 39 40 41 42	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Quotes included in tables; figures included to show experience created and assessed by community.

Discussion

44 45 46 47 48 49 50 51	Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Line 366
52 53	Limitations - Trustworthiness and limitations of findings	Line 442

Other

54 55 56 57 58 59 60	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Line 487
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Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Line 506
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*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

For peer review only

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: [10.1097/ACM.0000000000000388](https://doi.org/10.1097/ACM.0000000000000388)

For peer review only

BMJ Open

Development of a Cultural and Linguistically Sensitive Virtual Reality Educational Platform to Improve Vaccine Acceptance within a Refugee Population: The SHIFA Community Engagement-Public Health Innovation Program

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2021-051184.R2
Article Type:	Original research
Date Submitted by the Author:	29-Aug-2021
Complete List of Authors:	Streuli, Samantha; University of California San Diego, Anthropology Ibrahim, Najla; Somali Family Service of San Diego Mohamed, Alia; San Diego State University Sharma, Manupriya; Palomar College Esmailian, Markie; Illumesense Inc. Sezan, Ibrahim; Distinct Insights LLC Farrell, Carrie; San Diego State University Sawyer, Mark; University of California San Diego School of Medicine Meyer, Dan; The University of Texas Southwestern Medical Center El-Maleh, Khaled; QUALCOMM Inc Thamman, Ritu; University of Pittsburgh Department of Medicine Marchetti, Alex; Miami University Lincoln, Alan; Alliant International University - San Diego Courchesne, Eric; University of California San Diego School of Medicine Sahid, Ahmed; Somali Family Service of San Diego Bhavnani, Sanjeev; Scripps Clinic La Jolla - Genesee Executive Plaza, Healthcare Innovation & Practice Transformation Laboratory
Primary Subject Heading:	Qualitative research
Secondary Subject Heading:	Public health
Keywords:	Paediatric infectious disease & immunisation < PAEDIATRICS, QUALITATIVE RESEARCH, Community child health < PAEDIATRICS

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3 **Development of a Cultural and Linguistically Sensitive Virtual Reality Educational Platform to Improve**
4 **Vaccine Acceptance within a Refugee Population: The SHIFA Community Engagement-Public Health**
5 **Innovation Program**
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49 **Keywords:** vaccination, refugee health, community engagement, virtual reality, education
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51

52 20 **Manuscript Word Count:** 4821
53
54

55 **Figures and Tables:** 6
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Number of References: 23

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1
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3 25 **ABSTRACT**
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5

6 **Objectives:** To combat misinformation, engender trust, and increase health literacy, we developed a
7 culturally and linguistically appropriate virtual reality (VR) vaccination education platform using
8 community-engaged approaches within a Somali refugee community.
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10

11 **Design:** Community based participatory research (CBPR) methods including focus group discussions,
12
13 30 interviews, and surveys were conducted with Somali community members and expert advisors to design
14 the educational content. Co-design approaches with community input were employed in a phased
15 approach to develop the VR storyline.
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17

18 **Participants:** 60 adult Somali refugees and 7 expert advisors who specialize in healthcare, autism
19 research, technology development, and community engagement.
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22 **Setting:** Somali refugees participated at the offices of a community-based organization, Somali Family
23 Service, in San Diego, California and online. Expert advisors responded to surveys virtually.
24
25

26 **Results:** We find that a CBPR approach can be effectively used for the co-design of a VR educational
27 program. Additionally, cultural and linguistic sensitivities can be incorporated within a VR educational
28 program and are essential factors for effective community engagement. Finally, effective VR utilization
29 requires flexibility so that it can be used among community members with varying levels of health and
30 technology literacy.
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41 **Conclusion:** We describe using community co-design to create a culturally and linguistically sensitive VR
42 experience promoting vaccination within a refugee community. Our approach to VR development
43 incorporated community members at each step of the process. Our methodology is potentially
44 applicable to other populations where cultural sensitivities and language are common health education
45 barriers.
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List of Abbreviations:

CBPR: Community based participatory research

50 CHW: Community health worker

MMR: Measles, mumps, and rubella vaccination

SFS: Somali Family Service

VR: Virtual reality

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3 55 **ARTICLE SUMMARY**
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5 **Strengths and Limitations of this Study**
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- 7
- 8 ● We use a community co-design process that is supported by previous research to design a
9 virtual reality education experience for an underserved community.
10
 - 11 ● The qualitative aspects of this study provide in-depth information that can help to address
12 complex vaccine hesitancy issues among Somali refugees.
13 60
 - 14 ● We employed an iterative, phased approach to the development of educational content which
15 allowed us to continuously assess the project and how it impacted the refugee community.
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 - 17 ● This project is a pilot study with a small sample size which will need to be expanded to truly
18 understand the effect of our virtual reality health innovation on refugee vaccine perceptions and
19 behaviors.
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INTRODUCTION

Over 300,000 refugees enter the United States every year. While refugee resettlement has increased over time, events as recent as 2015 mark one of the largest exoduses of forced human migration, sparking a crisis as countries struggle to cope with the influx and the social and economic demands that coincide with human resettlement [1]. What is largely missing in the public discussion is an appreciation that refugees face extraordinary challenges throughout their migration process from origination to destination. One challenge in particular – the access to proper healthcare - is critical, both for those that have been resettled in the past and those who have recently arrived [2]. The other challenge is to collect and monitor healthcare data that can be accessed and disseminated to resettled communities for public health monitoring [3]. In recognition of these challenges, important questions range from how to efficiently meet the healthcare demands of a growing population that is effective and sustainable to providing an engagement that uses culturally specific resources that simultaneously enhances health education and drives an increased level of trust in the local healthcare system [4].

Upon resettlement in Western countries, many Somali refugees were faced with the widespread diagnosis of autism, a developmental disorder which was unfamiliar to them prior to migration [5]. On one hand, among a community cluster of resettled Somali children in Minneapolis, the prevalence of autism has exceeded 3% and has eclipsed the national average of 1.9% [6]. On the other hand, this specific refugee community was targeted by anti-vaccination activists and the propaganda that vaccination is a cause of autism. This misinformation led to concern by Somali parents and distrust in the healthcare system, which has resulted in a propensity for vaccine hesitancy and non-acceptance [5,6,7]. A lack of effective messaging towards what does cause autism and the dissemination of anti-vaccination propaganda were successful in decreasing vaccination rates in the Somali refugee population in Minnesota from 92% to 42% over the span of a decade [7,8].

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3 Effective healthcare education relies on various principles for building essential skills, including
4 communication, assessing the accuracy of information, decision making, planning, goal setting, and self-
5 management [9]. At its core, health education must be simple, retained, and must be assimilated within
6 those factors relevant to a given individuals biases and acceptances towards the delivered message [9].
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12 95 New digital innovations such as virtual reality (VR) have emerged as tools to provide enriching and
13 immersive learning experiences that promote understanding in acute conditions such as anxiety and post-
14 traumatic stress disorder, and chronic conditions such as tobacco cessation [10-12]. VR has also been used
15 to provide patients with a more positive experience in hospital settings by using virtual nurses that
16 patients can relate to [13]. The ability for VR to increase information retention and to change health
17 behaviors by engaging users in a non-healthcare environment makes VR a potentially valuable platform
18 for visual health education. Therefore, our primary aim was to develop a customized, culturally and
19 linguistically appropriate VR educational program specifically focused on pediatric vaccinations, and to
20 leverage community-based participatory research models and community co-designs to build, test, and
21 deploy VR at the community level among a group that are known to be vaccine hesitant or vaccine
22 resistant.
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39 **METHODS: STUDY DESIGN**

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41 SHIFA (Arabic for 'healing') is a community innovation program to design, deploy, and utilize new
42 healthcare innovations with an inclusive model of community engagement. Within the current program,
43 community-based participation was incorporated along three complementary approaches [14]. These
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47 include:
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51 1) To define the health care access barriers in a resettled refugee community with a focus on
52 pediatric vaccination.
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55 2) Incorporate a community-based participatory model to develop the virtual reality content
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3 115 with community member co-design.
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- 5 3) Develop a virtual reality environment that is customized with cultural, linguistic, and religious
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7 sensitivities to provide appropriate health education.
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10 Qualitative feedback was derived through focus group discussions, interviews, and surveys
11 developed by the investigators and was completed by community members and experts for analysis
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14 120 during each phase of technology development. Focus groups and interviews were conducted by Najla
15
16 Ibrahim and Samantha Streuli. Najla Ibrahim is a Somali woman who holds an MPH degree and is an expert
17
18 in community public health issues. Samantha Streuli is a white woman who holds a PhD in anthropology
19
20 and who has been working with the Somali community for four years. The majority of focus group and
21
22 interview participants were unknown to Samantha and Najla prior to the research project, though some
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25 125 were acquaintances from previous work within the Somali community.
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30 ***Ethics Approval Statement***

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32 This study was approved by The University of California San Diego Institutional Review Board
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34 (Protocol #171434).
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38 39 ***Patient and Public Involvement***

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41 The Somali community was involved in the research from its inception and were regularly
42
43 consulted as the research was developed. Focus groups and interviews with the community informed the
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45 development of research questions, which prioritized the experiences and interests of the Somali
46
47 community. We consulted with community members and community leaders when designing and
48 135
49 conducting the study and developing survey, focus group discussion, and interview questions to
50
51 determine outcome measures. Somali community members were also involved in the recruitment to the
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53 study, as much of the recruitment happened via word-of-mouth. The results of the study will be presented
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3 to participants and other community members, who will be further consulted via focus groups on how to
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5 140 best disseminate results.
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10 **Participants**

11 *Inclusion/Exclusion Criteria*

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13 We identified groups of Somali individuals for community participation and VR co-design.
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15 145 Participants were required to be members of the Somali community in San Diego, California who were
16
17 over the age of 18 and were either 1) Somali refugees; 2) Somali immigrants; or, 3) US-born Somali
18
19 Americans. We selected a group of 7 expert advisors to assist in the development of VR. These advisors
20
21 included: 1) researchers or other experts in autism and/or vaccination; 2) physicians serving the San Diego
22
23 Somali community and in pediatric health; 3) leaders within the Somali community.
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29 **Setting**

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31 San Diego County is the 3rd largest metropolitan area in California and the 12th largest
32
33 resettlement area in the United States. The organization responsible for the development and execution
34
35 of the program is Somali Family Service (SFS), a fiscal sponsor for the East African Collaborative of 8-
36
37 155 community organizations that aims to outreach, educate, and enroll refugees and immigrants in health
38
39 insurance programs. This specific community predominantly resides in City Heights, a subdivision of San
40
41 Diego County that has a population of 75,000 individuals. Socioeconomic statistics of this region includes
42
43 a median household income of \$39,330 (national median \$55,322), 40% are immigrants and/or refugees,
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45 with 31% having an education level of a bachelor's degree or greater [15].
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Recruitment

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6 Somali individuals were recruited via telephone and through word-of-mouth by Somali
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8 Community Health Workers (CHWs) and peers. As a non-interventional and non-comparative program,
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10 we did not determine an a priori sample size and identified consecutive participants interested in
11 165 participating within the community engagement design. As such, we included any individuals without a
12
13 predefined minimum or maximum sample size. In total, we included 60 community participants and 7
14
15 expert advisors. Our target participants were: a) parents of children between 0-2 years of age, b) pregnant,
16
17 or c) planning to become pregnant in the next two years; however, we included those Somali community
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19
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21 170 members interested in issues of autism and/or vaccination regardless of parental status. All participants
22
23 consented to have their names and contact information collected for future correspondences. This
24
25 information was securely stored in an encrypted file and only used to re-contact participants who agree
26
27 to be re-contacted. The research objectives, research participants' rights, and description of how data
28
29 would be used were explained to all participants prior to participation. All participants provided verbal
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32 175 consent, which was approved by The University of California San Diego Institutional Review Board
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34 (#171434).
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40 Expert advisors were identified by the SHIFA project leadership team according to their particular
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42 areas of specialization. Advisors signed consent forms to participate in the iterative development of
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44 180 educational content.
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CBPR and Community Co-Design

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51 Our Community-Based Participatory Research (CBPR) approach involved community members in
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53 each step of the design, iterative testing, and development of culturally and linguistically appropriate
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56 185 health education content. This approach to CBPR in the Somali community builds upon public health work
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3 previously done within refugee communities [16]. We developed a community co-design methodology
4 that uses the principles of design thinking combined with community-based research to enable
5 participants to be directly involved in the design and creation of content and products that are developed
6 to benefit them [16-17]. This co-design methodology was inclusive in that community members were
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12 190 asked to participate within content curation and to lead certain aspects of VR development.
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16 ***Phased Approach to Virtual Reality Development*** 17

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19 We merged each aspect of CBPR and community co-designs within a phased approach to VR
20 development (Vendor: INVIVO, Toronto, Canada). These phases included:
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24 195 **Phase 1:** CBPR approaches to assess community needs and concerns important to pediatric vaccination.
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27 **Phase 2:** VR modality determination for script development. The modality consisted of the type of VR
28 experience and the script development included the specific educational content.
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32 **Phase 3:** VR Prototype and iterative feedback from storyboards, 2- and 3-dimensional animation, and
33 visual and audio experiences that incorporate VR design elements including those factors that allow users
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37 200 to engage at different levels of health literacy.
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40 **Phase 4:** Final VR Product and Testing
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43 The objective within VR development was to use those tools and devices that were available to the
44 community-at-large and to ensure cultural and linguistic sensitivities were incorporated.
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Data Collection and Analysis

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6 All data were collected electronically via tablet or computer at the time of focus group discussions,
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8 interviews, and surveys. Focus group discussions and interviews were either recorded and transcribed, or
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10 210 extensive notes were taken on a computer in the event that groups or individuals declined to be recorded.
11
12 Focus group discussions took place at the offices of SFS. In total, we conducted 5 focus groups with 57
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14 participants. Some participants attended more than one focus group. Four of the focus groups were
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16 structured (see supplementary materials for discussion guides), while one was an unstructured discussion
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18 of the prototype. Interviews also took place at the offices of SFS and were conducted with 3 Somali
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21 215 parents. While the majority of participants were female, we also had a small number of male participants.
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25 Analyses were conducted thematically and iteratively using the content of the surveys, focus
26
27 group discussions, and interviews during the phased approach for VR development. This approach utilized
28
29 five steps: 1) familiarization, 2) coding, 3) theme development, 4) defining themes and, 5) reporting [18].
30
31 During the process of familiarization, all sections of the interviews, focus group discussions, and surveys
32
33 220 relating to the experience of utilizing VR were extracted. Coding was performed using MAXQDA software.
34
35 Emergent themes from each phase of development were defined and reported in order to inform the
36
37 subsequent development phases.
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41 The primary data coder was SAS. To ensure a rigorous evaluation of the data, a subset of
42
43 transcripts was also coded by AM. In order to achieve consensus on codes, AM and SAS engaged in
44
45 225 recurring discussions on the coding process. The analysis was further tested during discussions with expert
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47 advisors. The consensus was reviewed and approved by all investigators. Specific quotations were chosen
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49 by SAS to represent emergent themes in the data.
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RESULTS

This program began in April 2019 and product testing is ongoing. Figure 1 illustrates the phased approach to development and iterative testing. In total, 67 individuals (7 advisors, 60 Somali community members) provided feedback during each phase of VR development and participated within the community-co design.

Community-based Participation

The first step in our community engagement process was to hold a series of 3 focus groups exploring topics of interest to the Somali community including vaccination, autism, pediatric health, and technology (n = 18 Somali community members). We also conducted interviews with 3 Somali parents (see supplementary files for interview guide). Based on this initial feedback from the community, the project team held a design workshop to create a series of 3 story ideas for the VR. These ideas were then brought to the Somali community in the form of another design workshop where the community evaluated the suitability of the provided stories and suggested changes. 4 Somali community members (2 Somali community health workers, 1 Somali woman, and 1 Somali man) participated in this design workshop to develop the general framework of a story. Information learned from the community was then used to develop a first iteration of a script. This script was then tested for cultural and linguistic suitability and vaccine-promotion potential with 17 Somali women from ages 26-78 and was followed by a discussion with a prominent male community leader to again assess the cultural and linguistic appropriateness of the content to promote vaccine education. Finally, a 2-dimensional prototype of the VR animation was developed with a Somali voiceover (Figure 2) and was tested with 24 community members in order to determine the effectiveness of the messaging in promoting vaccination and to assess cultural and linguistic elements of the storyline.

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5 255 ***Phased Approach to Virtual Reality Technology Development***
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8 ***Phase 1:*** CBPR approaches to assess community needs and concerns important to pediatric vaccination
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11 The Somali community focus group discussions were broken up into three separate sessions,
12 each of which focused on a particular area of community interest (Table 1). The first focus group
13 discussion was centered on health concerns of the community, and participants cited autism as a major
14 concern, as well as language barriers that pose a significant problem when engaging with the medical
15 system. In addition, participants brought up issues of trust which were tied to poor communication.
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22 The second focus group discussion explored issues of pediatric health. Participants provided
23 information about pregnancy, childbirth, pediatric care, and parenting. The central theme of this focus
24 group discussion was issues of trust within the medical system, with many mothers indicating that while
25 they highly valued their doctors' opinions, they also preferred to do their own research. Mothers
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31 relayed to us their desire to receive health education in their own language from a trustworthy doctor.
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34 The third focus group discussion was centered around issues of vaccination and technology.
35 Participants once again indicated issues surrounding trust in medical systems and their desire to make
36 their own educated health decisions. Additionally, participants stated that they would like to receive
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40 270 more detailed information about how vaccinations work:
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45 "If they could show how the vaccine works in the child's body and what it does – if it can be
46 visualized."
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51 275 "That before the vaccines are given to our children, for it to be explained to us what the risks are
52 - the sided effects, and the benefits. When we compare the two, then make a decision."
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3 Themes that emerged from interviews with 3 Somali parents also included concerns about autism,
4
5 medical trust, and the desire to learn more about vaccination.
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10 **Phase 2: VR modality determination for script development**
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13 *Modality determination:* The project team consulted extensively with Somali CHWs to determine
14
15 an appropriate modality, and chose 360-degree video due to the ability of this format to be experienced
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17 using virtual reality headsets, smart phones, or computers in order to make this VR program widely
18
19 accessible to all members of the Somali community.
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23 *Script development:* Open-ended survey responses from Somali community members regarding
24
25 the three potential storylines indicated that an older Somali male doctor would be most suitable to
26
27 deliver health information in our story, as this character would evoke feelings of trust and respect.
28
29 Somali community members favored a scene where a Somali mother could be shown talking to her
30
31 doctor – this way they could see themselves as a character in the VR story and could see their questions
32 290
33 and concerns being addressed directly. The open-ended survey responses from community advisors
34
35 indicated a preference for a storyline with a strong focus on family and supported the story concept of a
36
37 Somali mother asking questions to a trusted physician. This information was used to develop the initial
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39 script.
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45 Six members of the expert advisory board reviewed the initial script. Advisors were asked to
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47 answer a series of six open-ended questions and provided insightful answers that assisted with script
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49 development (Table 2). Specifically, when advisors were asked for their overall impressions of the story,
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51 they stated:
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3 300 “Overall, I like how the story flows and the way in which the educational components are
4 presented.”
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10 “I like the simplicity of the conversation with its effective focus on the key messaging of the
11 value of the timely vaccination to help raise healthy kids.”
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16 We conducted a community focus group discussion during the script review process to engage
17 the community. Seventeen community members were asked to assess how culturally appropriate the
18 storyline was, what they would like to change, how impactful the story was, and how they would
19 personally design the content. During this focus group discussion, participants agreed that the story was
20 clear and easy-to-follow; however, as additional questions were asked about story flow, the feedback
21 turned to autism. We found that even when we did not mention autism, the false association between
22 autism and the measles, mumps, and rubella vaccine (MMR) came up as a topic of discussion. Many
23 community members said that they were concerned about autism and the MMR vaccination. One
24 woman asked:
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38 “If MMR doesn’t cause autism, why did I see my child stop talking immediately after getting the
39 MMR?”
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46 The participants agreed that the VR must address the autism question, and that they would prefer to
47 learn this information from a doctor character in the VR storyline.
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50 Community members were also asked to take a brief survey after reviewing the script. This
51 survey included questions about attitudes toward vaccination as well as vaccination planning. Notably,
52 there was an 18% increase in participants who endorsed being “very comfortable” with MMR
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3 vaccination following script exposure. Additionally, those who said they were “not at all comfortable”
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5 325 with MMR vaccination decreased by 12% following script exposure. There was also a 17% increase in
6
7 those who stated they would allow their child to receive the MMR following script exposure (Table 3).
8
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12 **Phase 3: VR Prototype and iterative feedback**

14
15 Three expert advisors provided feedback on the storyboard and prototype that focused on where
16
17 330 characters were positioned (i.e. husband next to wife), color scheme, and highlighted the need to describe
18
19 the immune system’s function in order to retain scientific accuracy in the communication of vaccination
20
21 information.
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25 The prototype (Figure 2) was tested with the Somali community in the context of an in-person
26
27 focus group discussion and surveys that took place in person at the SFS offices. Participants in the focus
28
29 335 group discussion were asked a series of open-ended questions about their experience with the prototype.
30
31 The primary focus of this discussion was analysis of the storyboards and stylistic elements of the VR
32
33 experience (e.g., color preferences, imagery, portrayal of characters). Participants indicated that they
34
35 highly valued the Somali voiceover and preferred to include the discussion of autism in the final VR
36
37 storyline, as its exclusion would raise more questions for the community. The participants also felt that
38
39 340 the father character in the VR storyline seemed somewhat excluded and should be standing near his wife
40
41 to signal support.
42
43

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45 All participants who reviewed the prototype agreed that the inclusion of culturally appropriate
46
47 characters and a Somali voiceover maximized the educational experience. 13/24 (54%) participants stated
48
49 that the prototype made them either more comfortable or much more comfortable with vaccination than
50
51 345 they were before exposure to the prototype. 20/24 (83%) participants stated that they would recommend
52
53 MMR vaccination to members of their community following exposure to the prototype. Additionally,
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55 21/24 (88%) said they planned to vaccinate their children following exposure to the prototype.
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6 *VR design factors:* The key VR design elements that were incorporated within each phase of VR
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8 350 development include passive, non-intrusive experiences, a dynamic and interactive visualization, and
9
10 prompts that promote the user towards self-reflection.
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16 **Phase 4: Final Product and Testing**

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19 The final product is a four minute 360-degree video animation (<https://youtu.be/NS8Gvtxnlk0>)
20
21 355 available in Somali and English languages. It can be viewed online using a tablet, a smart phone, or with
22
23 VR goggles. Settings include a Somali home populated by a family, and a doctors' office. In the animation's
24
25 introduction, we meet the expectant mother who states that she is expecting her first child and is trying
26
27 to make decisions about vaccination. Figure 3 illustrates in screenshots each of the 4 chapters in the VR
28
29 experience. We plan to test the final product using an A/B testing model with the Somali community
30
31
32 360 wherein the A group receives the VR education and the B group receives a basic English-language
33
34 educational video about vaccination. Both groups will be surveyed before and after exposure to the
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36 educational materials to assess changes in attitude toward vaccination and willingness to vaccinate.
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43 **DISCUSSION**

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46 365 The main results of the SHIFA program can be summarized as follows: 1) a community
47
48 participatory research model can be effectively translated for the co-design of a VR educational program
49
50 with community members involved in each phase of technology development; 2) cultural and linguistic
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52 sensitivities can be incorporated within a VR pediatric immunization educational program and are
53
54 essential factors for effective community engagement; and 3) effective VR utilization requires flexibility
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3 370 that can be used among community members with varying levels of health and technology literacy. To
4
5 the best of our knowledge, our VR development is the first such health innovation for vaccination
6
7 education designed by a community of refugees known for vaccine hesitancy.
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10 11 12 13 ***Refugee Learners – Vaccination & Autism*** 14

15
16 375 This community has common barriers to effective education such as a lack of information and
17
18 information that is not culturally and/or linguistically appropriate to drive understanding [19]. Regarding
19
20 immunizations, many parents and caregivers in this community already possess medically inaccurate
21
22 information. We have previously determined that within this refugee community the reason not to
23
24 immunize has resulted from misinformation and the perception that vaccination results in autism.
25
26
27 380 Although MMR vaccination rates have fallen in the Somali community (from 92% to 42% over the span of
28
29 a decade [7,8]) rates of autism and pediatric learning impairments have remained high (1:32 Somali
30
31 children have autism compared to the national average of 1:54) [20-21]. While these results do not
32
33 support the link between vaccination and autism, many parents are still convinced of an association
34
35 between MMR and autism. Given these results, it is important to take into consideration the mental and
36
37
38 385 emotional state and the ideation that arises from associating vaccinations with autism. Community health
39
40 engagement related to immunization requires education focused on the importance of vaccinations for
41
42 newly arrived refugees, and a re-education among those who have previously elected not to immunize.
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46
47 In this context, we performed a community health assessment and identified the drivers for a low
48
49 rate of vaccination in the Somali community ranging from cultural and language barriers, distrust in the
50
51 390 healthcare system, and the misinformation that vaccination results in autism. Recognizing these drivers
52
53 for low immunization rates in this community, our observations for the mechanisms for how VR affects
54
55 behavior changes include: content that is culturally relevant, stimulates an awareness and expectation for
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3 what vaccines do and do not do, and provides an immersive experience leading to information retention
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5 [22].
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10 11 ***VR CBPR and Co-Designs*** 12 13

14 In addition to the mechanisms for how VR affects behavioral change, several design factors must
15
16 be maintained when considering who interacts with the VR technology, especially among immigrants that
17
18 may have varying levels of health and digital literacy. Within our program, most community members
19
20 experienced a positive interaction with VR. There are several plausible reasons for our observations.
21 400
22 Through community co-designs, we leveraged key design factors including a non-intrusive experience
23
24 (users learn in their own environment), a passive interaction (content that is visual, audio, and depicted
25
26 versus reading), and a dynamic storyline that builds upon previous experiences, uses known environments
27
28 and promotes self-reflection by allowing the user to introspect and contemplate during the VR experience.
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31 405
32 Because we recognized the importance of culturally and linguistically appropriate educational
33
34 materials to deal with issues of low health literacy and medical distrust, we included community-based
35
36 approaches in each phase of our development. The results of focus groups and surveys conducted within
37
38 the community revealed several important considerations for the development of our VR storyline. For
39
40 instance, community members were much more comfortable receiving information from a trusted doctor
41
42 character. Community members also felt it necessary to include direct and clear information about the
43 410
44 lack of relationship between autism and vaccination in our storyline. This was in contrast to our
45
46 expectation and that doing so would reinforce this misinformation. Following design workshops with the
47
48 Somali community, we tested the program that they helped to co-design within the community in order
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50 to address its cultural and linguistic appropriateness as well as its ability to promote vaccination behavior.
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53 415 We also tested the VR storyline with a team of subject matter experts who evaluated the scientific
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3 accuracy and usability of our design. In our community testing, we found that many Somali community
4
5 members felt the VR storyline engendered trust, was relatable, was educational, and was convincing.
6
7 Several focus group and survey participants stated that they planned to vaccinate and to recommend
8
9 vaccination to others following exposure to the VR. Our testing with our panel of experts found that our
10
11
12 420 content was user-friendly, easy to understand, and scientifically accurate.
13
14

15 While we appreciate that community co-designs are an important methodology for how a new
16
17 technology is designed, a foundation of CBPR is necessary to harness community involvement. To employ
18
19 CBPR, we engaged community members throughout every step of the process. Before developing the idea
20
21 for the VR storyline, we engaged the community in a series of three focus groups to better understand
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23
24 425 their needs, strengths, and interest in collaboration. Focus group discussion questions were open-ended
25
26 and allowed for participants to bring their interests and concerns into the conversation. Information
27
28 learned from these engagements was used to begin to develop the culturally and linguistically appropriate
29
30 storyline for the VR. Community members were also continuously engaged throughout the development
31
32 of the VR storyline through community co-design.
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34

35 430 It is our plan to develop and leverage an educational curriculum in future deployments of VR. Due
36
37 to the constraints of COVID-19, we are currently exploring the possibilities of using telehealth and other
38
39 digital communication platforms to safely and effectively deploy the VR into the community. Addressing
40
41 vaccine hesitancy is especially relevant within the context of COVID-19, as vaccination rates for
42
43 preventable diseases have dropped significantly since the beginning of the COVID-19 crisis [23]. There are
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45
46 435 also concerns about the potential of misinformation related to COVID-19 vaccination that is especially
47
48 relevant for an underserved community that is largely excluded from vaccine clinical trials and
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50 communities that have a history of vaccine hesitancy.
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Limitations

440 Our community feedback and focus groups represent a convenience sample for those that are
more apt towards vaccine acceptance, and therefore may not completely capture all concerns among
those who are vaccine hesitant. While this represents a potential selection bias, our method to include a
wide range of community members as well as internal and external advisors may enhance internal validity
445 by incorporating a heterogenous group for community input. Community-based participation and
community co-designs at each stage of VR development from the initial idea through completion of a VR
animation may enhance external validation by including the key components related to cultural and
linguistic sensitives within the phased approach for VR development. COVID-19 impacted our abilities to
recruit more participants and to test our final VR experience within the community in the way that we
450 had initially planned to. We are attempting to mitigate this limitation by administering online surveys in
the Somali community after they view the VR at home; however, this may limit the quality of our data as
most individuals do not have VR headsets at home and may not get the full immersive effect without
them. Finally, a perceived shift from vaccine hesitancy to vaccine acceptance at this point is subjective
and requires real-world validation and prospective follow-up confirming vaccine delivery.

455

CONCLUSION

We employed community-based participatory approaches, and community co-design to develop
an innovative vaccine educational technology with Somali refugees using VR. By combining new
technology-enabled approaches with the needs, interests, and expertise of Somali community members,
460 we have created a methodology that can address vaccination beliefs and behaviors in a vaccine hesitant
refugee population. Future research will include an assessment of the efficacy of the VR platform on

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3 vaccination rates over time, as well as continued community engagement for the development of
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5 additional VR content which can increase health literacy within underserved populations.
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11 **465 ACKNOWLEDGEMENTS**
12
13

14 We first extend our sincerest gratitude to the Somali community for their inspiring engagement
15
16 in this project. Next, we would like to thank Fadumo Jama, Ahmed Dahir, and Sahra Nor for their assistance
17
18 with participant recruitment, facilitation of community engagements, and translation and interpretation
19
20 services. Finally, we are grateful to Dr. Ahmad Bailony and Karen Henken for their guidance and input on
21
22
23 **470** this project.
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29 **CONTRIBUTORSHIP STATEMENT**
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31

32 SS, NI, and AM contributed to the collection and analysis of data for this work. SS and SB
33
34 contributed to the initial drafting of the manuscript. SS, NI, MS, ME, IS, MSa, AS, and SB contributed to
35
36 **475** the conception and design of the work. All authors (SS, NI, AM, MS, ME, IS, CF, MSa, DM, KE-M, RT, AM,
37
38 AL, EC, AS, and SB) contributed to the interpretation of the data, revising the work critically for important
39
40 intellectual content, providing final approval of the version to be published, and all agree to be
41
42 accountable for all aspects for the work in ensuring that questions related to the accuracy or integrity of
43
44 any part of the work are appropriately investigated and resolved. The funders had no role in the design
45
46
47 **480** and conduct of the study; collection, management, analysis, and interpretation of the data; preparation,
48
49 review, or approval of the manuscript; and decision to submit the manuscript for publication.
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COMPETING INTERESTS

485 Carrie Farrell was a paid consultant on the project from inception until August of 2019. Alex
Marchetti is a former employee of technology partner INVIVO and her engagement with the project began
while she was with that organization in 2018. Sanjeev Bhavnani discloses Scripps Clinic Grants for clinical
trials related to machine learning and technology designs in cardiovascular imaging, being a Pfizer Health
Information Technology Advisory Board member on strategies related to health information technology,
490 being a Bristol Meyers Squibb Digital Health Advisory board member on strategies related to digital health
technologies, being an Anthem AI Consultant on projects related to cardiovascular care, being a Proteus
Health Chair DSMB on digital medication monitoring in hepatitis C, being an American College of
Cardiology Innovations Advisory Group Principal investigator and committee member on various
innovation projects in cardiovascular care, having Analytics4Life Stock options as a scientific advisor on
495 artificial intelligence in cardiovascular diagnostics, and having Blumio Stock options as a scientific advisor
on new technology designs in hypertension. Markie Esmailian discloses US patents in Illumesense Inc.,
using data analytics and machine learning algorithms for clinical decision support for alternative health
therapies. Markie Esmailian is also Founder of IllumeSense Inc. as majority shareholder and principle.
Ibrahim Sezan discloses that he is a paid employee of Distinct Insights, LLC. Ahmed Sahid, Najla Ibrahim,
500 and Samantha Streuli were all paid employees of Somali Family Service at the time of this research. Alia
Mohamed was also a paid research assistant for this project. All other authors declare that they have no
relevant or material financial interests that relate to the research described in this paper.

FUNDING

505 Alliance Healthcare Foundation Grant #18-34728477.

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3 **DATA SHARING STATEMENT**
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5
6 Data are deidentified participant data and are available from the corresponding author upon
7
8 request. Reuse is not permitted.
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For peer review only

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TABLE 2. Questions and Responses from Project Advisors

Questions Asked to Advisors	Salient Responses
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TABLES

TABLE 1. Focus Group Questions and Responses from Somali Community

Category and Questions for Community Members	Salient Responses
Session 1: General Health	
Examples of questions asked in focus groups	
“What are some of your community’s biggest health concerns in the U.S.?”	<p>“Autism.”</p> <p>“One of the biggest health problems that people have that I forgot to mention is that most people don't understand a lot of English.”</p>
“What do you find not trustworthy within the health care system?”	<p>“Lack of good communication...especially in primary language.”</p> <p>“Health insurance!”</p>
Session 2: Pediatric Health	
Examples of Questions asked in focus groups	
“Do you trust your doctor’s recommendations for your child’s health?”	<p>“Yes, whatever recommendation the doctor gives me, I have to take it.”</p> <p>“I mean I always think it's obviously for a good reason, but for me, I think I always do my own research before I automatically assume that's what's best for me. If it's something very serious like [the doctor] saying for example 'you need a surgery,' that [I] automatically would be like 'let me get another opinion from another doctor.’”</p>
Session 3: Vaccination	
Examples of questions asked in focus groups	
“What are the topics or things that you would like to know about in relation to vaccines?”	<p>“If they could show how the vaccine works in the child’s body and what it does – if it can be visualized.”</p> <p>“That before the vaccines are given to our children, for it to be explained to us what the risks are - the sided effects, and the benefits. When we compare the two, then make a decision.”</p>

Table 1: Sample questions and salient responses from exploratory focus groups indicated that parents were very concerned about autism and that they found it difficult to trust the healthcare system due to lack of communication in their primary language. While parents trusted certain doctors, they also highlighted the importance of doing their own research to understand their children’s health. Parents also expressed a desire to understand how vaccines work within the body and what the risks and benefits are of vaccination.

<p>1) What are your overall impressions of the story? What did you like the most about the story? Is there anything that you think should change in the story?</p>	<p>“Overall, I like how the story flows and the way in which the educational components are presented. I also think it’s a great idea to have the story centered around a meal, as it seems culturally relevant and helps make the situation relatable to users.”</p>
<p>2) Have you noticed any inaccuracies in scientific and medical facts in the story?</p>	<p>“Based on my past feedback, I am glad that this story has been selected. I like the simplicity of the conversation with its effective focus on the key messaging of the value of the timely vaccination to help raise healthy kids.”</p>
<p>3) Was the story clear and easy to understand? Did the story flow naturally?</p>	<p>“No.”</p> <p>“No, from my knowledge all of the content presented is accurate.”</p>
<p>4) Was the story culturally appropriate? Was the cultural component balanced throughout?</p>	<p>“Very clear and flowed in a way we would use in teaching in general. Very logical progression of information.”</p> <p>“Yes, the story is clear and flows very naturally.”</p>
<p>5) Was the story convincing? Does it have a potential to change attitudes of vaccine hesitant parents?</p>	<p>“One of the things I liked about this story is the emphasis of the great Somali family bond that can be pivotal in achieving the goals of this project to leverage the great trust Somali parents put on their relative and educated community members.”</p> <p>“Yes, the story was culturally relevant and appropriate.”</p>
<p>6) In your opinion, does the story increase knowledge?</p>	<p>“I think it gives the information about immunization, the science behind it, and does not focus on the controversies, which have not been supported by medical data.”</p> <p>“Yes. I would just make sure we really take advantage of VR when we show the visuals inside the body and how vaccine’s function within the immune system.”</p>
<p>6) In your opinion, does the story increase knowledge?</p>	<p>“Yes, it stays with the facts in a positive way, in a healthy environment with the families.”</p> <p>“It can, depending on the background of the parents and audience and their desire to benefit from such educational program.”</p>

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Table 2: Sample questions and salient responses from engagement with project advisors. Advisors enjoyed the clarity and flow of the storyline as well as finding it culturally relevant and appropriate. They also believed that the story had significant potential to increase vaccine knowledge.

TABLE 3: Survey following initial script exposure

How comfortable are you with MMR vaccination?	%	How comfortable are you with MMR vaccination?	%	Would you get MMR for your child?	%	Would you get MMR for your child?	%
Very comfortable	52%	Very comfortable	70%+	Yes, I would	65%	Yes, I would	82%+
Somewhat comfortable	24%	Somewhat comfortable	18%-	I would consider it	23%	I would consider it	12%-
Not at all comfortable	24%	Not at all comfortable	12%-	I don't know	6%	I don't know	0%-
				No, I would not	6%	No, I would not	6%

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Table 3: This table shows the results of a survey of 17 Somali mothers following exposure to the initial script for the VR. + indicates % increased following exposure to the script, - indicates % decreased following exposure to the script.

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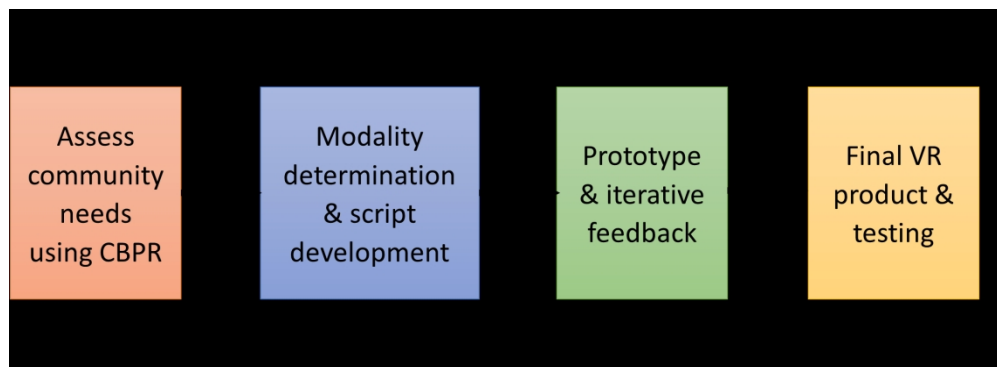
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FIGURES

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11 615 **Figure 1:** Phased approach to VR development. Assessment of community needs began in April 2019 in
12 advance of the development of the VR. Iterative testing took place throughout 2019 and 2020, with some
13 gaps in testing due to the restrictions of the COVID-19 pandemic. The final VR product has been completed
14 as of June 2020 and is currently being tested with the Somali community.

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18 620 **Figure 2:** Still frame from prototype. The prototype consisted of a motion storyboard with a voiceover
19 which was translated into Somali for presentation to the community.

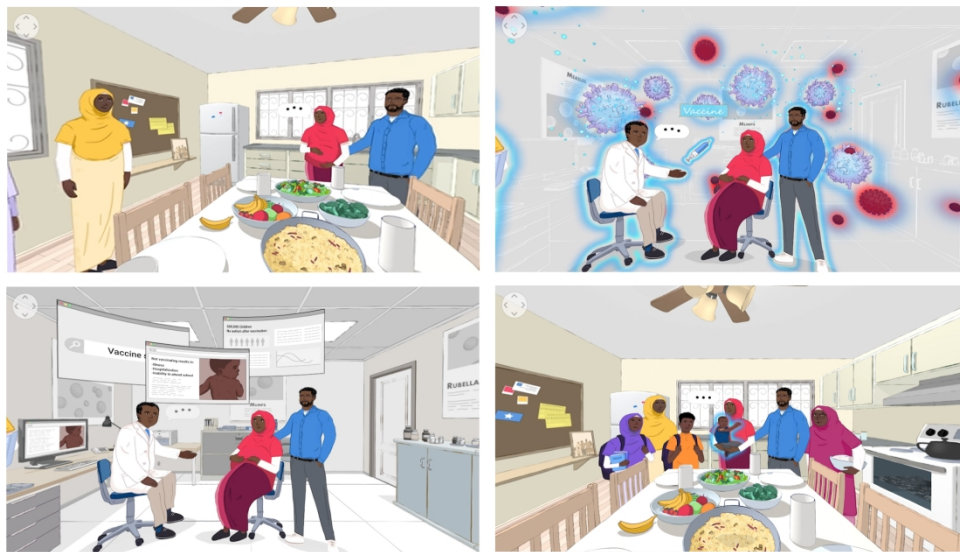
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27 625 **Figure 3:** Top row: Chapters 1 and 2 of the VR story. Bottom row: Chapters 3 and 4 of the VR story. In
28 chapter 1 of the animation, the expectant mother, her husband, and her sister visit the doctor's office
29 and learn about measles, mumps, and rubella (MMR). In chapter 2, the family learns how the immune
30 system works. In chapter 3, the family learns from the doctor what the MMR vaccine does and how it
31 works. In Chapter 4, the doctor explains to the family the risks and benefits of MMR vaccination,
32 including a statement debunking the association between autism and vaccination. Finally, the 360-
33 630 degree video concludes by showing the new mother and her family – including the new, healthy baby –
34 and the new mother states that after learning all the facts, she has decided to vaccinate her child.
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Phased approach to VR development. Assessment of community needs began in April 2019 in advance of the development of the VR. Iterative testing took place throughout 2019 and 2020, with some gaps in testing due to the restrictions of the COVID-19 pandemic. The final VR product has been completed as of June 2020 and is currently being tested with the Somali community.



Still frame from prototype. The prototype consisted of a motion storyboard with a voiceover which was translated into Somali for presentation to the community.



Top row: Chapters 1 and 2 of the VR story. Bottom row: Chapters 3 and 4 of the VR story. In chapter 1 of the animation, the expectant mother, her husband, and her sister visit the doctor's office and learn about measles, mumps, and rubella (MMR). In chapter 2, the family learns how the immune system works. In chapter 3, the family learns from the doctor what the MMR vaccine does and how it works. In Chapter 4, the doctor explains to the family the risks and benefits of MMR vaccination, including a statement debunking the association between autism and vaccination. Finally, the 360-degree video concludes by showing the new mother and her family – including the new, healthy baby – and the new mother states that after learning all the facts, she has decided to vaccinate her child.

Focus Group 1 Discussion Guide

Questions about health in Somalia and refugee camps:

1. Q: What was your opinion of healthcare in Somalia?
2. Q: Did you receive health education (in Somalia)? What kind?
3. Q: If you spent time in a refugee camp, were you provided health services there?
4. Q: What kind of health services did you receive in Somalia (e.g. preventative, emergency, obstetric, etc.)?

Questions about resettlement process

1. Q: Were you provided with health services and/or screening as part of the resettlement process?
2. Q: Were you provided with health education as part of the resettlement process? What kind?
3. Q: If you have children, were you offered healthcare services for your children? What kind?

Questions about healthcare in the US

1. Q: What kinds of healthcare services have you received in the US (e.g. preventative, emergency, obstetric, etc.)?
2. Q: For what health conditions are you most likely to seek medical care?
3. Q: Where do you go for healthcare services?
4. Q: If you have children, what kind of healthcare services have they received?
5. Q: Have you received health education or information (in the US)? (From whom, about what?)
6. Q: What are some of your community's biggest health concerns in the US? Mental (or Autism)? Physical? Chronic Conditions?
7. Q: Who is the decision-maker in your household for health care?
8. Q: What sources of information do you use to make healthcare-related decisions? (e.g. family, friends, religious leaders, doctors, healthcare workers)
9. Q: Do you trust your healthcare provider and his/her guidance/recommendations?

10. Q: Is there any part/aspect of the healthcare system in the US that you do not find completely trustworthy?
11. Q: Who does your community (not just you) go to for healthcare? (who is trusted?) Are there specific hospitals people go to?

Focus Group 2 Discussion Guide

Introductory Questions

1. Do you have children (under 18 years old)? How many? What are their ages?

Prenatal Health Questions

1. If you've had children, did you experience your pregnancies here in the United States?
2. What is prenatal care? What do you know about prenatal care?
3. How do you feel about c-sections? (I ask because women seem to bring this up a lot and it is mentioned often in literature around Somali women's birth experiences in Western countries)
4. What did you learn through prenatal care that was valuable to your child rearing?
5. Where did you give birth? Where do mothers in your family or friends give birth?

Pediatric Health Questions

1. What do you know about pediatric (infant and childhood) health? Where do you get information about pediatric health (friends, family, internet, social media, doctors, etc.)?
2. How do you make decision about your child's healthcare?
3. Do What does the phrase "stages of development" mean to you? (If they're not sure we could explain and then ask the next part) What do you think the "stages of development" for children are? When do they happen?
4. Where do people learn about stages of development?
5. Who (or where) do your children go to see for healthcare?
6. When do you take your children to their doctor? How old are they typically? Yearly visits? How often? (routine preventive care, health and developmental guidance, screening for health conditions, treatment of acute and chronic conditions, and injury care)
7. What is a healthy child?

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8. What type of problems or challenges have you experienced with your own children when it comes to their health? What about in your community?
9. What barriers might prevent you from seeking or accessing healthcare for your children?
10. Do you have any advice or tips for young mothers and their young children when it comes to their healthcare?
11. If you were to watch educational video about pediatric health, how would you prefer to access or watch that?
12. How would you like to receive information about infant and child health in the future? (maybe give some options like using technology, watching videos, attending health fairs, attending workshops, formal classes, advice from doctors, etc.)
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Focus Group 3 Discussion Guide

Questions about Vaccine Knowledge and Attitudes:

1. From your understanding, what are vaccinations for? What are their benefits? How do they work?
2. Do you understand how the vaccination works in your body?
3. Are vaccines effective against diseases/illnesses?
4. What information have you received about vaccinations and where?
5. Do you feel that the information you received was enough to make a good decision?
6. What information is missing that you would like to know about vaccination?
7. Do you feel like you get better information about vaccinations when you have a translator or someone like this present?
8. When did you first get vaccinated?
9. When did your children first get vaccinated? Why did you vaccinate them (i.e. school requirement)?
10. Why did you vaccinate (did school, doctors tell you?)
9. Why did you vaccinate in the US?
10. Where did you get vaccinated?

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3 11. If you were not told by a doctor or school to get vaccinated (prompted by someone else), would you
4 still vaccinate your children and why?
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7 12. As you might know, vaccines are conducted based on a schedule (based on age of child) – what are
8 your thoughts about the schedule? Frequency of the shots children are getting?
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10 13. What do you think about frequency, amount, timing of shots?
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12 14. Have you heard of parents delaying vaccinations for their children?
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14 **Questions about Anti-Vaccination:**

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17 15. Have you heard the recent news about disease outbreaks in the US caused by unvaccinated
18 children?
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20 16. If so, where did you hear that information? What are your thoughts about that?
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22 17. What are reasons people decline vaccinations?
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24 18. Are vaccines related to or a cause of any illness (besides autism)?
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26 19. Do you know others in the community who are hesitant about vaccinations?
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29 **Questions about Technology:**

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31 20. If we were to create something educational for you and your community, what would be the best
32 way to teach?
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34 21. If you were to design the VR program what would you do or show?
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36 22. What kinds of experiences would you like to see? How vaccines work? Simulated interaction with
37 healthcare provider?
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44 **Script Review Focus Group Discussion Guide**

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46 1) What were your overall impressions of the script?
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48 2) Does the script have the potential to impact your community's beliefs about autism and vaccination?
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50 3) What did you like about the script?
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52 4) What would you change about the script?
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54 5) Is there anyone or anything that you think is missing from the script?
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Parent Interview Guide

Introductory Questions:

1. How old are you?
2. Do you have children? How many children do you have?
3. Are you married?
4. How long have you been in the US?

Interview Questions:

1. Where or who do you generally get your medical information from? Why?
2. What is autism?
3. From your understanding, what causes autism?
4. Do you know anyone in your community who has autism?

If their child:

1. Were you familiar with autism prior to your child's diagnosis?
 2. What signs or behaviors have caused you to seek medical help for your child?
 3. Can you explain the process of receiving an autism diagnosis for your child?
 4. What challenges have you faced as a parent of an autistic child?
 5. What challenges has your child faced as a child with autism?
 6. What treatments have you used to manage your child's autism?
5. How do people in your community view or understand autism?
 6. Is there anything you would like to know or understand about autism?
 7. How do you feel about vaccinations?
 8. Would you, or have you, vaccinated your children? Why did you make that choice?
 - Have you been made aware that vaccination and immunization records are now required for children to attend school in San Diego? How do you feel about that?
 9. How do you think other members of your community feel about vaccination?
 - What concerns or fears do other members of your community may have about vaccination?

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4 10. Do you know anyone in the Somali community in San Diego who has chosen not to vaccinate?
5 Why? Do you think they would be willing to speak with us?
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8 11. Do you feel like you've been provided enough information about vaccinations to make an
9 informed decision?
- 10 • Do you feel like members of your community are provided with enough information
11 about vaccination to make an informed decision?
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- 13 12. If you've changed your mind about vaccinations at any point, do you recall what that deciding
14 factor was? If you haven't changed your mind (or if you are still anti-vaccination or hesitant),
15 what may change your mind?
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- 18 13. What would you like to know or understand about vaccinations?
- 19 • What do you think members of your community would like to know or understand
20 about vaccinations?
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- 22 14. What do you know about Virtual Reality? Have you ever used it?
- 23 • Would you feel comfortable using VR for an education program? Do you think
24 members of your community would be comfortable using VR?
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 - 26 • Do you have any questions about Virtual Reality?
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29 15. What other formats would be best for developing a health education program for your
30 community? (video, game, lecture, workshop, discussion)?
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- 33 16. Is there anything else you think we should know or consider?
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35 0. Any questions for me?
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Standards for Reporting Qualitative Research (SRQR)*

<http://www.equator-network.org/reporting-guidelines/srqr/>

Page/line no(s).

Title and abstract

<p>Title - Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended</p>	Page 1
<p>Abstract - Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions</p>	Page 3

Introduction

<p>Problem formulation - Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement</p>	Page 6
<p>Purpose or research question - Purpose of the study and specific objectives or questions</p>	Page 7 Line 102

Methods

<p>Qualitative approach and research paradigm - Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., postpositivist, constructivist/interpretivist) is also recommended; rationale**</p>	<p>Page 8 line 120</p> <p>Page 9 line 160</p> <p>We employed CBPR and community co-design in order to develop educational content that was created by and for the communities for whom it was intended. We used focus groups, interviews, and surveys in order to triangulate our data and to include the voices of the community in as many ways as possible.</p>
<p>Researcher characteristics and reflexivity - Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability</p>	Page 8 Line 121
<p>Context - Setting/site and salient contextual</p>	Page 8 Line 135

factors; rationale**	
<p>1</p> <p>2 Sampling strategy - How and why research</p> <p>3 participants, documents, or events were</p> <p>4 selected; criteria for deciding when no further</p> <p>5 sampling was necessary (e.g., sampling</p> <p>6 saturation); rationale**</p> <p>7</p> <p>8</p> <p>9</p> <p>10</p> <p>11</p> <p>12</p> <p>13</p> <p>14</p> <p>15</p> <p>16</p> <p>17</p> <p>18</p> <p>19</p> <p>20</p>	<p>Page 8 line 125.</p> <p>Somali community members were chosen in the manner that they were because we recognize the importance of including the entire community in research. There is a strong oral tradition in Somali culture and parents often ask advice from extended family and community when making decisions about healthcare. Thus, we found it necessary to engage individuals of all ages and genders who spoke English and Somali to guide the educational material and provide their input.</p> <p>Expert advisors were chosen in order to provide us with another view of the issue from a technical angle so that we could better create something that could be realistically delivered to the community.</p>
<p>21 Ethical issues pertaining to human subjects -</p> <p>22 Documentation of approval by an appropriate</p> <p>23 ethics review board and participant consent,</p> <p>24 or explanation for lack</p> <p>25 thereof; other confidentiality and data security</p> <p>26 issues</p> <p>27</p>	<p>Page 9 Line 150</p>
<p>28 Data collection methods - Types of data</p> <p>29 collected; details of data collection procedures</p> <p>30 including (as appropriate) start and stop dates</p> <p>31 of data collection and analysis, iterative</p> <p>32 process, triangulation of sources/methods, and</p> <p>33 modification of procedures in response to</p> <p>34 evolving study findings; rationale**</p> <p>35</p> <p>36</p> <p>37</p> <p>38</p> <p>39</p> <p>40</p> <p>41</p> <p>42</p> <p>43</p> <p>44</p> <p>45</p> <p>46</p> <p>47</p> <p>48</p> <p>49</p> <p>50</p> <p>51</p> <p>52</p> <p>53</p> <p>54</p> <p>55</p> <p>56</p> <p>57</p> <p>58</p> <p>59</p> <p>60</p>	<p>Page 10 Line 180</p> <p>We collected data via focus groups, interviews, and surveys in order to triangulate data. We also wanted to reach as many community members as possible so we engaged people online, at the offices of the nonprofit organization, and at community health fairs.</p>

1 2 3 4 5 6 7 8 9	Data collection instruments and technologies - Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	Interview and focus group discussion guides were included as supplementary files. Types of questions asked are also described throughout the manuscript.
10 11 12 13 14 15 16 17	Units of study - Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	Number of participants is described throughout the paper at each relevant event (n of focus group participants etc.)
18 19 20 21	Data processing - Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/de-identification of excerpts	Line 206
22 23 24 25	Data analysis - Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale**	Line 213
26 27 28 29	Techniques to enhance trustworthiness - Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale**	Line 221

Results/findings

31 32 33 34 35	Synthesis and interpretation - Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	Described beginning on line 226.
36 37 38 39 40 41 42	Links to empirical data - Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	Quotes included in tables; figures included to show experience created and assessed by community.

Discussion

44 45 46 47 48 49 50 51	Integration with prior work, implications, transferability, and contribution(s) to the field - Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/generalizability; identification of unique contribution(s) to scholarship in a discipline or field	Line 366
52 53	Limitations - Trustworthiness and limitations of findings	Line 442

Other

54 55 56 57 58 59 60	Conflicts of interest - Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	Line 487
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Funding - Sources of funding and other support; role of funders in data collection, interpretation, and reporting	Line 506
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*The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

For peer review only

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**The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.

Reference:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. **Standards for reporting qualitative research: a synthesis of recommendations.** *Academic Medicine*, Vol. 89, No. 9 / Sept 2014
DOI: [10.1097/ACM.0000000000000388](https://doi.org/10.1097/ACM.0000000000000388)

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