Community Engagement Framework

Investigating the Health Needs and Challenges of Individuals Seeking Asylum and Refugees:

An Evaluative Framework

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1. Introduction

Within England, the NHS has adopted an approach (**CORE20PLUS5**) to inform action to reduce healthcare inequalities at both national and system level (NHS2021). This approach is characterised by three components:

- **Core20**

The most deprived 20% of the national population as identified by the national Index of Multiple Deprivation (IMD).

- **PLUS**

PLUS population groups are identified at the local level. Population groups may include ethnic minority communities; people with a learning disability and autistic people; people with multiple long-term health conditions; other groups that share protected characteristics as defined by the Equality Act 2010 and those groups experiencing social exclusion for example: people experiencing homelessness, drug and alcohol dependence, vulnerable migrants, Gypsy, Roma and Traveller communities, sex workers, people in contact with the justice system, victims of modern slavery and other socially excluded groups.

- **5**

There are five clinical areas of focus which require accelerated improvement. Governance for these five focus areas sits with national programmes; national and regional teams coordinate activity across local systems to achieve national aims. The five clinical areas include: 1. Maternal; 2. Severe mental illness; 3. Chronic respiratory disease; 4. Early cancer diagnosis; 5. Hypertension case-finding and optimal management and lipid optimal management.

The Core20PLUS5 populations in England report the poorest health and suffer from the worst health outcomes. This is accentuated by the same patients suffering from inequitable access to health and care services and treatment pathways. Treatment pathways in the NHS utilise innovative medicines and medical technologies, which help to improve the quality of healthcare for patients across England. Yet understanding and accessing these services can be difficult for people in the Core20PLUS populations.

Individuals seeking asylum and refugees in society experience distinct challenges when attempting to access health care. Such individuals who are seeking refuge are not a homogeneous population. Coming from different countries and cultures, their health is influenced by experiences prior to leaving their home country, such as fleeing war, conflict and persecution. Other traumatic experiences during transit or after arrival in England also impact negatively on their health (BMA, 2022, Royal College of Psychiatrists, 2022). As such many individuals seeking asylum and refugees have a wide range of experiences that contribute to their sometimes-complex health needs. Common health challenges include untreated communicable diseases, poorly controlled chronic conditions, maternity care, mental health and specialist support needs (BMA, 2022). These challenges are further exacerbated by language and cultural differences, the effects of poverty, and a lack of cohesive social support. Further, racial discrimination can result in inequalities which have a detrimental impact on health, opportunities and quality of life. (Burnett and Peel 2001, BMA, 2022, Royal College of Psychiatrists, 2022).

When individuals seeking asylum and refugees arrive in England, they are looking for protection and a place of safety (Refugee Council, 2023). For example, children need vaccinations, pregnant women need to see a midwife, and some refugees have never had the opportunity to access any healthcare. Thus, processes that prevent or delay access to healthcare causes further and more challenging problems in the long term. Individuals seeking asylum and refugees are often wrongly refused access to primary care as well as often refused interpreters, which is essential in some cases to understanding their health concerns. Many individuals seeking asylum and refugees are also digitally excluded as they do not have access to a mobile phone or device, (or credit on their mobile phone). This barrier serves to preclude them from the many healthcare services and information that are sent and accessible online (Refugee Council, 2023). Many individuals seeking asylum and refugees experience difficulties in expressing health needs and in accessing health care (Kang et al, 2019).

In England, individuals seeking asylum and refugees suffer the adverse effects of attempting to settle within a different culture and community. There are various reasons for this: the most common issue is the language barrier, limited English language proficiency and literacy, exacerbated by different dialects and accents (Asif and Kienzler, 2023). Individuals who form this group frequently comment that they would not bother checking their health due to this challenge, asserting that they cannot always find people to accompany them on health consultations and furthermore, struggle navigating Information Technology systems and receptionists when attempting to book an appointment. Disturbingly, at times they feel that some of them are not treated fairly, and that because they are individuals seeking asylum or refugees, they do not have the confidence or the right to question their treatment or discuss their health issues. This is often highlighted in vaccination campaigns. For example, it has been observed that some individuals seeking asylum attended for vaccinations and were unaware of the purpose or nature of the vaccination. Furthermore, simple tasks such as requesting repeat prescriptions for existing health conditions and ongoing support is a key challenge.

This project is a collaboration between Health Innovation Yorkshire & Humber (formerly known as Yorkshire & Humber AHSN) and University of Huddersfield. The aim is to develop a framework which will enable staff within West Yorkshire Health and Care Partnership to effectively engage with relevant populations groups, and to integrate them within service re-design. The framework was 'tested' utilising the experiences of migrant and refugee population groups. This also allowed the project team to understand and help individuals seeking asylum and refugee communities to access appropriate health care support. The overall purpose of the project is to develop an evidence-informed whole-society approach to health care access. In essence to support individuals seeking asylum and refugees, and those working in public health services to work with and benefit from each other in the delivery of appropriate health care.

Access to good health care is a cornerstone of successful integration and participation in society and the economy and plays a key role in the journey followed by individuals seeking asylum and refugees in their lives. However, accessing health care in an unfamiliar environment can generate significant stresses for individuals, and if access is delayed can cause or exacerbate ill health. As mentioned, these experiences are often exacerbated by racism and discrimination, poor educational access, and low levels of host language proficiency. These are particularly turbulent times for individuals seeking asylum and refugees and the role that health care delivery plays in their integration is not well understood. This project using a prescribed evaluative framework approach (CARA), which is a tri partite framework to evaluation that ensures that evidence generated from an evaluation is Culturally competent, Relevant, Accessible and Authentic. Using the CARA framework aims to narrow this gap and enable a better understanding of how people who are new to the UK gain access to health care and enable an enhanced understanding of their lived experiences of engaging and accessing appropriate health care. Furthermore, this project provides an evaluation of the CARA framework to inform future adoption.

2. Aim and Objectives

Utilising an holistic approach, this project aims to:

Develop a framework which the ICS can utilise to ensure effective integration of populations into decision making and service design. An integral part of this development included exploring the experiences of individuals seeking asylum and refugees by focusing on the challenges they have experienced in accessing health care.

Objectives

1. To develop, adopt and test an evaluative framework: CARA to enable staff within the ICS to include Core 20 plus 5 population groups in order to inform and promote change in health and social care practice.
2. Understand and address the challenges and responses faced by individuals seeking asylum and refugees when accessing health care.
3. To understand and support the development of decision making of health care professionals to assist individuals seeking asylum and refugees.
4. To understand and support the responses by health care agencies and organisations in helping individuals seeking asylum and refugees address their health needs.
5. To further develop the evidence base with regards to how individuals seeking asylum and refugees have navigated their health care and their engagement with health care agencies.
6. To commence a real-world research dialogue within the area of reducing inequalities faced by individuals seeking asylum and refugees.

3. Evaluation Framework

Harnessing the spirit of collegiality and collaboration to ensure clarity, structure and credibility within the process of evaluation, the project team developed a framework that represented the key interdependent components of the evaluation process.

The following diagram (fig 1) illustrates the processes undertaken by the project team in establishing a model of change to improve the quality of healthcare for asylum seekers and refugees across England:

Fig 1. The CARA practice framework.

The model comprises three layers:

Layer One:

A.SP.I.RE.

This informs eight interdependent components. It is a four-step cyclical process that involves Assessment; Solutions orientated Problem solving; Implementation, Reflection and Evaluation.

- **Assessment**: This comprises a holistic method of data collection from all available sources. For the purpose of this study, individual semi structured interviews (Robson and McCartan 2016) were conducted exploring with individuals seeking asylum and refugees within the community, their families, support workers and practitioners involved in the management of health and social care provision.
- **Solutions orientated Problem solving**: This involves the development and design of solutions to problems and challenges identified from data collected in the assessment phase. Data collected in this study were analysed using template analysis (King and Brooks, 2017) and several themes were identified (see section 8).
- **Implementation**: This is an active phase delivering the solutions designed. For the purpose of this study, this stage involves: dissemination of findings, peer review; design of materials and policy based on the evaluation data collected.
- **Reflection and Evaluation**: This is the fourth stage of A.SP.I.RE and involves holistic evaluation and testing in addition to embracing the reflective elements of Kirkpatrick's model. The project partnership team embraced the results and findings generated from the peer review and discussions with project team partners.

Layer Two:

This layer provides the epistemological, ontological and axiological basis of the framework and is crucial to ensuring validity.

- **Competence**: Crucial to the project is the notion of cultural competence. This is the ability to learn from and effectively interact, work, and develop meaningful and respectful relationships with people of various cultural background, beliefs, customs and behaviours. In order to achieve this, the project team must reflect cultural competency. To achieve this the team investigated and progressed the notion of co participant inquiry within a collaborative and collegial model.
- **Authentic**: Authenticity in this context means adopting an honest real-world experience that reflects the values, and spirit of the role. Integral to this dynamic is the notion of wisdom and trusted voices. Respecting the voice of the beneficiary enables authenticity. To achieve this the project team adopted an honest and open approach with each-other embracing the experience and wisdom each had to offer to inform the process.
- **Relevant**: This refers to the congruence of the setting of interest with the phenomena and provides an accurate representation of the case. It requires reinforcing the importance and value of accessing community and beneficiary wisdom. Key to achieving this is recognising the value and interpretation of the real world – within a social realist perspective. The team due to its collaborative and collegial manner was able to provide an accurate representation of the phenomena under evaluation.
- **Accessible**: This is concerned with ensuring equal access to services, resources and facilities for everyone. In the context of this study, accessibility is concerned with identifying and the challenges and difficulties faced by asylum seekers and refugees in accessing appropriate health care.

Layer Three:

This layer is concerned with the sustainability and development of the community, population or phenomenon under investigation.

- **Heutagogy**: This is a process of sharing knowledge and wisdom within a self-determined approach, but importantly it is "participant" centred and focussed. This means that it is participant centric and based upon their real-world experiences. The principle of heutagogy applied to this project is based upon ensuring that needs of all participants (for example, health professionals, support workers and policy makers) are responded to and that individuals seeking asylum, and refugees are enabled to decide and act in an informed way.
- **Method**: This is the collegial and collaborative mechanism established to ensure a community participatory approach. The project team have a collegial identity with each member, have shared decision making responsibilities and this is characterised by the absence of any hierarchy.
- **Population Need**: These are the perceived and expressed holistic needs of the community. The project team adopted an holistic approach to the change process and acknowledge weaknesses and failings of mitigation and assessment strategies with the processes adopted.
- **Community**: This is the community of practice that is formed to enable the development of the project and should include representation from all stakeholders and beneficiaries. Establishing the community enables sustainability contributing to dissemination and the development of change in practice.

4. Method

This section of the report illustrates the evaluation framework adopted, the methods of data collection and analysis techniques used to collate the findings.

Evaluation is described by the NHS (nd) as a process that helps practitioners to consider what works, what does not work and how practice can be improved within a constant theme of judging and comparing worth. This approach reflected the key aim of the project:

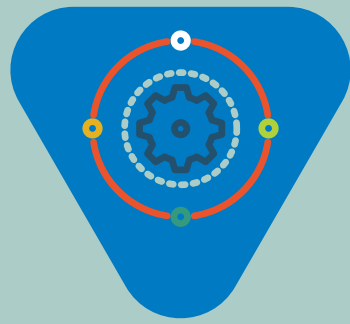
- To explore the experiences of individuals seeking asylum and refugees by focusing on the challenges they have experienced in accessing health care, utilising the CARA framework.

The processes adopted to achieve the aim of this project was informed by the principles postulated by Snowden and McSherry (2017) to develop an innovative approach based on the traditional notion of action research, where knowledge and understanding is created within a specific and practical context (Koshy 2005). This enabled the project team to embed the notion of collaborative, co-participatory strategy within a collegial framework. Consequently, the approach to involvement in this project is different to many studies that involve participants and service users. Rather than being consulted as respondents, participants were involved as equal partners in a critical evaluation process to explore and make sense of their perceptions, reflections and experiences as a basis for generating new insight, knowledge and action (Percy-Smith 2018).

Furthermore, close collaboration and collegiality within the team ensured effective community participation. Indeed, the project team's underlying ethos of collaboration and collegiality is based on developing relationships with respect and maximising opportunities for participation with all partners. This meant involving those individuals' seeking asylum and refugees and appropriate health and social care workers as partners in all stages of the evaluation process. This included identifying key questions, facilitating and undertaking data collection with their peers and other influencers in response to those questions, interpreting findings, assessing materials prompting discoveries and conversations, with the implicit objective of progressing and owning plans for acting upon the findings of the evaluation. Key to the success of this approach was the clear and unified vision of the project team that embraced a collegial and co-participatory philosophy that acknowledges community wisdom and the ability to listen, consult and respect cultural sensitivities.

The partnership team comprised of academics, individuals seeking asylum and refugees and their family members, support workers, practitioners involved in the management of health and social care provision associated with individuals seeking asylum and refugee health and social care needs and policy makers.

5. Methods Used as Part of CARA



The following methods were used for data collection:

1. Document Review

Document review is an important qualitative research method (Bowen, 2009). Documents are formal communications with a specialised knowledge base and policy framework (Bauer, Gaskell and Allum, 2000). Documents are stable and provide exact evidence of references or details of events that could be reviewed repeatedly. They may include, letters, personal notes, email correspondence, a report of events, proposals, internal records or articles. (Yin, 2009, 2014). Documents are considered "un-obtrusive and un-reactive" as they do not get affected by being observed by a researcher (Robson and McCartan, 2016, p. 349), yet can be strong evidence to support or validate the data findings generated by using other inquiry methods. However, documents may not clarify the level of personal engagement and extent of group contribution in developing or utilising the document as a resource (Robson and McCartan, 2016). Also, document analysis requires interpretation from the researcher who reviews the document using analytic strategies (Finnegan 1996). Those review strategies include selecting and considering relevant documents to approach and understanding the relative social context and its production requirements (Bowen, 2009; Atkinson et al., 2001).

For this study, document review included information pertaining to individuals seeking asylum and refugees (Robson and McCartan, 2016). The purpose of performing document analysis is to inquire in what ways and to what extent literature is presented and if it is visibly accurate and representative.

2. Interviews

The interview method is highly recommended when the focus of the study is to explore the meaning associated with a particular phenomenon. Interviews are also useful if the purpose of the study is to explore multiple perspectives on the same issue by conducting a series of interviews, in the given context (Robson and McCartan, 2016). Semi-structured 1:1 interviews were chosen as the most appropriate method for data collection, as this enabled the curation of individual views on the quality, validity and content of patient material presented. The semi structured interviews conducted utilised a flexible focused guide based on key suppositions and the use of the evaluative tool PROMPT (Open University 2018). In evaluative studies information collated is dependent upon the quality of the interview process. To ensure consistency and an interview guide was developed in partnership with the team using the principles of PROMPT and key supposition based on the experiences and wisdom of the team and available literature. This exercise contributed to the validity and credibility of the data collection tools within the CARA evaluative framework (Robson and McCartan, 2016; Snowden et al 2023).

Sample
Using purposive sampling, in total 14 interviews were conducted with individuals seeking asylum and refugees, 4 support workers, 6 health and social care professionals and policy makers.

6. Data Analysis

1. Interview

For this study, data collected from interviews were analysed using Template analysis, a form of thematic analysis to organise and analyse the qualitative data collected from the interviews. King & Brooks' (2017) suggests that template analysis is a flexible method for thematic analysis and offers a useful degree of structure in the process of analysing textual data with the flexibility to adapt it to the needs of a study. Transcribed verbatim data, gathered from the interviews were coded using this approach, and used to analyse similar and comparative themes or patterns to establish key findings. The research team, drawing upon those preliminary summary themes developed a coding template. These themes were identified in relation to the presuppositions of the evaluation enabling the exploration of the relevant subjective perspectives and experiences of the participants. Template Analysis also allowed the team to identify and to infer meanings and findings in the context of the presuppositions.

2. Document Review

Content analysis was used to determine themes and concepts presented within the findings of the review completed of qualitative, mixed methods and qualitative research and the review of publicly available health related information for refugees. Using content analysis enabled inferences to be developed regarding the content within the texts analysed, the authors, audience, content and the possibility of assessing validity and accuracy (Bengstom 2016). This method also contributed to the development of the key suppositions of the project and therefore to assess the validity of the presupposition made to inform the interview template (Yin 2018). The method involved the analysis of presented text and similar to Template analysis text is required to be "coded" that is broken down into manageable categories for analysis and then following further analysis enabled the development of key themes.

7. Ethics

Ethical approval for this project was granted by the University of Huddersfield, School of Human and Health Sciences Research Ethics and Integrity Committee.

8. Results

Following analysis, the data yielded the following themes:

1. **Language:** Literature availability is judged to be poor, in terms of accessibility, availability and accuracy. The value of having an interpreter was noted, however availability and having an interpreter that spoke the correct dialect was found to be limited.

2. **IT Access and Support:** With increasing health service delivery based online, use of mobile technologies, navigating systems and access to internet was found to be problematic.

3. **Cultural Awareness:** Health care workers were perceived to lack a meaningful understanding of different cultures for example food, language, rituals, religion and experiences.

4. **Health Issues:** Key health issues presented including impact and response to violence (physical and psychological), Sexual Health, Maternal care, Chronic Health, Dental care and Childrens health – including vaccinations. Observed that health care workers were often more interested in the migrants journey than the presenting health issue.

5. **Discrimination/racism including abuse and violence.** Lack of trust, treated with suspicion (public and Health Care Worker).

6. **Mental Health and Well-Being:** - This is identified as the most striking theme. Characterised by loneliness/ isolation, helplessness, depression and in some cases psychoses.

7. **Belonging:** The desire to belong to and participate as part of a community, and to be seen as part of "British" community was strong. Strong desire to engage and contribute for example appropriate employment and use of skills.

8. **Housing/Accommodation and Environment:** Challenges to access appropriate accommodation were distinct. Often unsuitable – for example separating/isolating family members and friends. Poor assessment of needs. Feelings of being treated like criminals and "underclass" from entering the country.

9. **Humanity:** The notion of the "alien" perverse stance on humanity values and respect. A lack of compassion and rushed, inconsiderate treatment from the onset.

10. **Financial Support:** Incongruence as wish to be independent but huge problems with accessing work and legal employment.

9. Resolution

1. Health specific literature/accessible/language specific.
2. Register of interpreters that are available to translate the ‘correct’ language. (24/7).
3. Fobs/lanyards QRS for health care workers that aid rapid access to appropriate information. Decision tree.
4. A co-ordinated system of “mentor”/buddy and (befriender for hospital setting) framework.
5. Appropriate education, learning and work opportunities.
6. Improved support to enable integration and community cohesion.
7. Adopt and humanistic approach to arrival.
8. Localised care and management.
9. Community involvement throughout the life cycle.
10. Greater involvement of Schools.
11. Accountability and monitoring.
12. Multi-sectoral health needs assessment.
13. Multi-sectoral/collaborative approach for improvement.

10. Evaluation of CARA

This small-scale pilot project enabled an opportunity to test in a systematic way the CARA framework. Methods included 360 review using the Kirkpatrick Model (Kirpatrick 2012) and by peer review including: academic, community representative, policy maker and a clinician.

Their comments were analysed using content analysis and three key themes were identified and summarised:

Theme One: Language and Presentation

Community representatives noted the use of terms that were not familiar eg: “heutagogy” within the diagram and the terms of: ontology, epistemology and axiology within the report. This was also highlighted by a clinician and a policy maker. The presentation of the model was identified by an academic and a community representative as not distinctive with the colours in particular obscuring the words used.

Interestingly in contrast, academic reviewers found this to be clear and understandable.

Theme Two: Process

Reports from the reviewers were not consistent. Some reviewers commented that the process of evaluation using the model was clear, whilst others suggested that the boundaries between the layers where “blurred”. One respondent suggested developing a timeline to supplement the model.

Reflecting upon the process, the team agreed that the Solutions Oriented Problems solving needed clear parameters to aid clarity when developing the aims and objectives of the project.

Theme Three: Content

The methods and structure of the model were judged to be sound. That the process adopted as part of CARA was rigorous and a credible evaluation framework that can be used to develop system design.

The project team reflecting upon their experiences identified the importance of establishing the parameters as part of the A.SP.I.RE stage and the value of the participatory approach in the early stages of the project. It was also apparent that “lay” members of the project team needed support in design and systems thinking alongside research and evaluation training in those areas specific to the project.

11. Conclusion

The aim of this project was to develop a framework (CARA) that can be utilised to ensure effective integration of populations into decision making and service design. To test the efficacy of this model the experiences of asylum seekers and refugees accessing health care was explored.

Using the CARA model, the data generated ten key themes and thirteen key recommendations to enhance accessibility and health of this population group.

Clearly, the framework adopted is robust and provides a credible change and evaluation framework with the potential for evidence to inform change that is Culturally competent, Relevant, Accessible and Authentic.

12. Recommendations

1. Present and canvas views within a webinar in order to provide further evaluative data to support, design, refinement and implementation.
2. Modify CARA framework based on 1.
3. Develop a series of reflective case study design to illustrate use and made available via web-based hub.
4. Develop a Web based hub where resources can be located to inform the adoption of CARA e.g methods of analysis and data collection, developing successful partnerships etc
5. Construct a web-based mentoring network that will support individuals and teams using CARA.
6. Develop a web-based hub Community of Practice of individuals who have used or intend to use CARA.
7. Promote and disseminate findings using available media.

13. References

Asif, Z. and Kienzler, H. (2023). Barriers to healthcare for refugees, asylum seekers and undocumented migrants. Kings College London. London.

Bengtsson, M. (2016) How to plan and perform a qualitative study using content analysis, NursingPlus Open, Volume 2, 8-14,. https://doi.org/10.1016/j.npls.2016.01.001.

BMA (2022). Unique challenges for refugees and asylum seekers. Patient health document. bma.org.uk. Accessed 22.6.23

Burnett, A. and Peel, M. (2001). Health needs of asylum seekers and refugees. British Medical Journal. 322 (7285) (544-547). https://doi.org/10.1136/bmj.322.7285.544

Kang, C., Tomkow, L., Farrington R (2019). Access to primary health care for asylum seekers and refugees. British Journal of General Practice. 537-545.

King, N. and Brooks, J. (2017). Template analysis. Sage: London.

Koshy, V. (2005) Action Research for Improving Practice: A practical Guide. London: Sage.

NHS (2021) Core20PLUS5 An Approach to Reducing Health Inequalities www.england.nhs.uk/wp-content/uploads/2021/11/core20plus5-online-engage-survey-supporting-document-v1.pdf

NHS (nd) NHS: Evaluation Works Tool Kit: https://nhsevaluationtoolkit.net

Open university (2018) PROMPT: Advanced Evaluation: www.open.ac.uk/libraryservices/documents/advanced-evaluation-using-prompt.pdf

Percy-Smith, B. (2018). Participation as Learning for Change in Everyday Spaces: Enhancing Meaning and Effectiveness Using Action Research. In C. Baraldi, & T. Cockburn (Eds.), Theorising Childhood: Citizenship, Rights and Participation (1st ed., pp. 159-186). (Studies in Childhood and Youth). Palgrave Macmillan, Cham. https://doi.org/10.1007/978-3-319-72673-1_8

Raliegh, V and Jones (2021) The health of people from ethnic minority groups in England. Kings fund: www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england

Refugee Council (2023). The truth about asylum. Refugeecouncil.org.uk. Accessed 22.6.23

Robson, C. and McCartan K. (2016) Real World Research. (4th. ed.). Wiley

The Learning and Work Institute (2023) Mapping Skills Needs in England https://learningandwork.org.uk/news-and-policy/literacy-numeracy-england-map/

Royal College of Psychiatrists (2022). Asylum seekers and refugees mental health. Information for health and social care professionals. RCPSYCH. www.rcpsych.ac.uk

Snowden, M., & McSherry, R. (2017). Establishing Excellence: Where Do We Go from Here? In J. P. Halsall, & M. Snowden (Eds.), The Pedagogy of the Social Sciences Curriculum (pp. 107-118). [Chapter 9] (International Perspectives on Social Policy, Administration, and Practice). Springer International Publishing AG. https://doi.org/10.1007/978-3-319-33868-2_9

Yin, R. K. (2009) Case Study Research. Design and Methods 4th Edition Sage Publications, Thousand Oaks.

Kirkpatrick, J.D. and Kirkpatrick,W.K. (2016) Kirkpatrick's Four Levels of Training Evaluation. Association for Talent Development, Virginia.

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